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Epilepsy impact on quality of life in women
Vliv epilepsie na kvalitu života u žen

Diploma thesis

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Prohlášení

Prohlašuji, že jsem závěrečnou práci zpracovala samostatně a že jsem uvedla všechny použité informační zdroje a literaturu. Tato práce ani její podstatná část nebyla předložena k získání jiného nebo stejného akademického titulu.

Praha, 13.08. 2020 Podpis autorky

Abstract

This thesis looks into the concept of the quality of life in women with epilepsy from a qualitative perspective. Epilepsy, as is a chronic neurological disease, affects not only everyday activities after the diagnosis, but also has its impact on the women's life regarding employment or family. By adapting the narrative analysis this thesis categorizes the influential factors of this concept into primary and secondary ones. Moreover, it explores in detail the issue of obtaining a driving license, which is one of the specifics of the people with epilepsy in Czechia. Also, it defines the respondents' attitudes toward the societal perception of epilepsy and fears that accompany it. In addition to that, the matter of motherhood and pregnancy for women with epilepsy is explored as one of the influential factors of the quality of life. Lastly, this thesis argues that the qualitative approach is essential for the initial examination of the selected sample for future investigations regarding the concept of the quality of life in epilepsy.

Keywords

Epidemiology, epilepsy, quality of life, women, motherhood, pregnancy, factors, narrative analysis, interview, qualitative methodology

Abstrakt

Tato práce se zabývá pojetím kvality života u žen s epilepsií z kvalitativního hlediska. Epilepsie jako chronické neurologické onemocnění postihuje nejen každodenní činnosti po diagnóze, ale také má dopad na životní rozhodnutí žen v takových oblastech jako je zaměstnání nebo rodina. Prostřednictvím narativní analýzy práce kategorizuje související faktory vybraného konceptu na primární a sekundární. Dále podrobně zkoumá problematiku získání řidičských průkazů, což je jednou ze specifik u osob s epilepsií v Česku. Práce zároveň definuje postoje respondentů vůči společenskému vnímání epilepsie a s tím související obavy respondentů. V neposlední řádě je zkoumána otázka mateřství a těhotenství u žen s epilepsií, a to jako jeden z ovlivňujících faktorů kvality života. Nakonec táto práce představuje kvalitativní přístup jako nepostradatelný nástroj pro počáteční prozkoumání vybraného vzorku v návaznosti na budoucí výzkumy spojené s koncepcí kvality života v epilepsii.

Klíčová slova

Epidemiologie, epilepsie, kvalita života, ženy, mateřství, těhotenství, faktory, narativní analýza, rozhovory, kvalitativní metodologie

Poděkování

Ráda bych na tomto místě poděkovala RNDr. Michale Lustigové, Ph.D. za ochotu při vedení této práci, množství cenných a inspirativních rad, doporučení, věnovaný čas a zároveň za podporu ve volbě metodologie a trpělivost s obdivuhodnou ochotou při konzultacích poskytnutých ke zpracování této práce. Mé poděkování patří také všem respondentkám, které mi věnovaly svůj čas v tak nejistém období a podělily se o své životní příběhy a zkušenosti.

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List of abbreviations

ADL/IADL	Activities of Daily Living
AED	Anti-Epileptic Drug
AEP	Adverse Event Profile
BDI	Beck Depression Index
BIS	Barratt Impulsiveness Scale
DRE	Drug Resistant Epilepsy
DSM	Diagnostic and Statistical Manual of Mental Disorders
EQ-5D	European QoL 5 Dimension scale
EQ-VAS	EuroQol-Visual Analogue Scales
ESPERA	European observational Study on Epileptic Patients Requiring at least two Antiepileptic drugs
ET	Emotional Thermometer
F-Sozu K-14	The Social Support Questionnaire, Short Form-German
FACES III	Family Adaptation and Cohesion Scales
GAD	General Anxiety Disorder
HADS	Hospital Anxiety and Depression Scale
HAMD	Hamilton Depression Rating Scale
HRQOL	Health Related Quality of Life
HRSD	The Hamilton Rating Scale for Depression
IBE	International Bureau for Epilepsy
ICD	International classification of diseases
ILEA	International League Against Epilepsy
IMDYVA	Prevalence of depressive symptoms and their impact on quality of life in patients with drug-resistant focal epilepsy
IPQ	Illness Perception Questionnaire
JME	Juvenile Myoclonic Epilepsy
LSSS	Liverpool Seizure Severity Scale
LAEP	Liverpool Adverse Events Profile
LAM	Lymphangioleiomyomatosis
MADRS	Montgomery-Åsberg Depression Rating Scale
MDD	Major Depressive Disorder
MDI	Major Depression Inventory
MEPSY	Multicenter Trial of Epilepsy and Psychiatric Diseases
NDDI-E	Neurological Disorders Depression Inventory for Epilepsy
NHP	National Health Plan
PACIC	The Patient Assessment of Care for Chronic Conditions
PHQ-9	Patient Health Questionnaire version 9
PWE	People with epilepsy
PWE-K-NDDI-E	Korean version of the NDDI-E
Q-LES-Q-SF	Quality of Life Enjoyment and Satisfaction Questionnaire short form
QoL	Quality of Life
QOLIE	Quality of Life in Epilepsy Inventory
SAS	Sport Anxiety Scale
SDL	Sleep Diagnosis List
SDS	Sheehan Disability Scale
SEIQoL-DW	The Schedule for the Evaluation of the Individual Quality of Life-Direct Weighting
SRHI	Self-Report Habit Index
SwLs	Diener Satisfaction with Life Scale
WAIS	Wechsler Adult Intelligence Scale
WHO	World Health Organization

WHOQOL	World Health Organization Quality of Life Inventory
WHOQOL-BREF	World Health Organization Quality of Life Instruments

Chapter 1

1. Introduction

Epilepsy is a major public health imperative according to the World Health Organization (World Health Organization 2019, p. 3), and one of the pressing problems in the context of the stigma due to the nature of the illness. The treatment gap for people with epilepsy (PWE) was acknowledged to be a severe problem that, at the same time, affects daily their quality of life (QoL) (Sander 2008). Furthermore, epilepsy has its significance both for the diagnosed person and the treating doctor in the context of psychological and sociological consequences (Bishop, Allen 2003). This includes not just the physical impact of the illness on a person's body and well-being but additionally on their socio-economic status and their social network.

A key aspect of epilepsy is the concept of the QoL among diagnosed people as it has an impact on various areas of their lives. The issue of the QoL itself has received considerable critical attention in the field of epidemiology (Ventegodt, Merrick, Andersen 2003), social epidemiology (Allison, Locker, Feine 1997) and demography (Ramadas et al. 2015). Understanding this concept in the connection to the particular disease can be beneficial for health policies and health care providers along for the future studies that can explore the most prominent factors of the QoL in details and make the illness more manageable both for a person and a society she/he lives in.

Recent developments in the field of public health studies led to a renewed interest in assessing the QoL regarding various medical conditions. Epilepsy can be considered as one of them as there is still no explanation for the particular causes of the epileptic seizures along with the functional medication for each type of seizures. In order to maintain a plausible routine and satisfaction with a current state, QoL is one of the most significant concepts to consider. For these purposes, the biopsychosocial perspective is used to combine several factors such as biological, psychological, and social for the future explanation of the QoL among PWE (Bala et al. 2016). This is a fundamentally distinct approach from the biomedical one that was used in earlier studies.

What we know about the QoL in epilepsy is mainly based upon empirical quantitative studies that investigate various factors that can impact their lives, including the strength of the impact. Several attempts have been made in order to investigate this issue from a qualitative perspective, using mostly the narrative analysis. However, researches have consistently shown that there are no gender differences between the male and female PWE regarding the QoL. In addition to that, there is a gap in assessing the QoL between men and women using the qualitative approach, as this concept is traditionally examined by distinct quantitative tools. Debate continues about the best strategies for assessing the QoL in PWE by exploring the set of factors or only one of them in each of the studies. Nevertheless, there is a general trend in the previous researches for understanding the concept by objectifying it into a score number, rather than subjective construction from a person with an epilepsy standpoint.

Researches have not treated the subjective QoL from a patient's perspective, including a female one, in much detail. The general assumption that women with epilepsy are struggling with the issues of pregnancy and motherhood was discussed mostly in quantitative studies without further exploration. However, considerable uncertainty still exists concerning the impact of epilepsy on the QoL in women, where the possibility of the future pregnancy or motherhood has been acknowledged in case of the woman's interest in it.

This thesis will attempt to show the impact of epilepsy on the QoL in women. In the pages that follow, it will be argued which influential factors could be considered as primary or secondary ones based on the subjective assessment among Czech women with diagnosed epilepsy. The aim of this research project, therefore, will be to attempt and establish which factors will have the most impact on the QoL and how they will be explained based on the hierarchy that will be provided during the interviews by the respondents. This thesis will explain the construction of this concept regarding women with diagnosed epilepsy and the value of this construction for them in the context of each factor mentioned during the data collection phase. Moreover, it will seek to obtain data which will then help to address previously revealed research gaps, especially in the Czechia's research field. This thesis is aimed to address the following research questions:

1. How is the concept of quality of life in epilepsy constructed?
    - Which factors can be categorized as primary or secondary?
2. To which extent and how the epilepsy impacts life and the QoL in women with epilepsy?
    - The strength of the impact from a subjective respondent's perspective
    - The value and meaning of each factor for a respondent

By employing qualitative modes of inquiry, I attempt to illuminate the idea of the quantification of the QoL and the subjective meaning of the illness. That is why this thesis is exploratory and interpretative in nature. It consolidates the critical analysis of the previous QoL in epilepsy studies with its qualitative examination on the same issue. The analysis of the 6 gathered interviews along with the representative of the Czech volunteer organization that provides social help for PWE, and the analysis itself was done by using the narrative analysis.

Due to practical constraints, this thesis cannot provide a comprehensive review of all studies that were conducted regarding the QoL among PWE. It is also beyond the scope of this thesis to examine the QoL in all women with epilepsy across Czechia. Moreover, the reader should bear in mind that the data collection phase was coincidently met the COVID-19 outbreak that brought

additional limitations to the research. Nevertheless, the limitations of this paper will be discussed later in the methodology section of this thesis.

The overall structure of the thesis takes the form of seven chapters, including this introductory chapter. Chapter two starts by laying out the theoretical background of the research that looks at the nature of epilepsy and its relation to the QoL including the instruments that are traditionally used in order to determine it. The third chapter is concerned with the topic of QoL in epilepsy in the context of the previously conducted studies, and the factors that in the majority of cases impact the QoL in PWE. The fourth section illustrates the issue of the QoL studies in Czech PWE. Furthermore, the fifth chapter presents the methodology used for this study along with its limitations. The sixth chapter describes the findings of the research, focusing on the codebook that was created during the narrative analysis. Chapter seven analyses the results of the interview and focuses on the categorization of the influential factors based on the previous researches. Finally, the conclusion gives a brief summary and critique of the findings.

Chapter 2

2. Theoretical background

To assess the QoL in Czech PWE, it is crucial to recognize the nature of epilepsy as a neurological condition. In addition to that, one of the typical presentations of epilepsy as an epileptic seizure. That is why it is essential to determine the illness and an epileptic seizure for future references in the discussion section. Furthermore, epidemiology of the illness along with the summary of the QoL assessment instruments are required for understanding not only the characteristics of the primary and secondary factors, that will be defined further but also the necessity of the qualitative QoL evaluation. Nevertheless, the instruments for the QoL assessment are based on the definition of the QoL or health-related QoL, both of which will be presented in this section.

Current knowledge about epilepsy is based mainly on the international definitions of the illness. However, from a medical point of view, there can be particular distinctions in each country. I would like to note here that the explanation of distinctions in epilepsy and epileptic seizures classification is beyond the scope of this thesis. Nevertheless, the international definition appears to be the most relevant for the purposes of this thesis.

2.1. Epilepsy and epileptic seizures

International Classification of Diseases, version 10 (ICD-10), places epilepsy among with status epilepticus in the sixth chapter "Diseases of the nervous system" in the category G40-G47 "Episodic and paroxysmal disorders". Epilepsy itself is under the code G40, and status epilepticus is under the code G41.

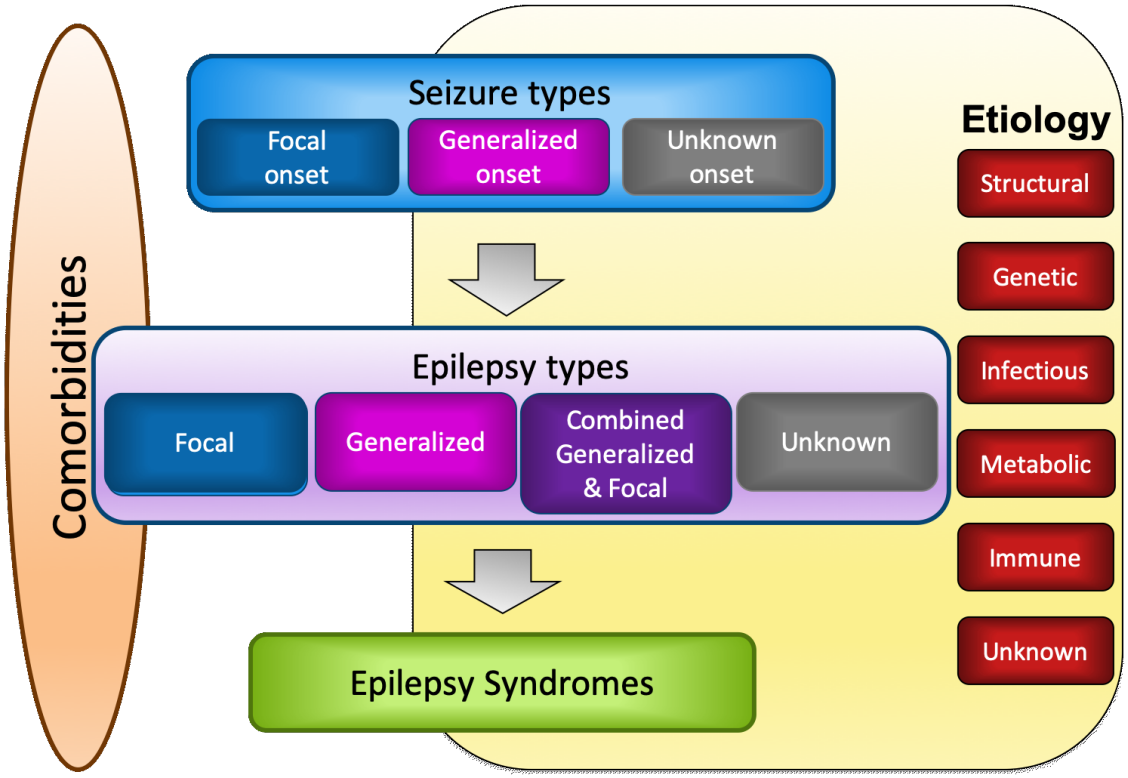
According to the International League Against Epilepsy (ILAE), epilepsy should be defined as "a disease of the brain defined by any of the following conditions: 1. At least two unprovoked (or reflex) seizures occurring less than 24 hours apart. 2. One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two

unprovoked seizures, occurring over the next 10 years. 3. Diagnosis of an epilepsy syndrome" (Fisher et al. 2017, p. 447). An epileptic seizure is defined in the following manner: a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain.

Still, it should be taken into account that studies before 2014, as a year of the publishing of the latest practical definition of epilepsy and even after the article was published, may use distinct definitions of the disease and the presentation of epileptic seizures. Nonetheless, this thesis is based on the stated description of epilepsy.

ILEA classification in Figure 1 is preferred in the majority of studies due to its multilevel nature and complexity that is needed in the case of epilepsy and epileptic seizures types. It should be noted that this classification is based on the definition of epilepsy and epileptic seizure defined in the sub-chapter "Epilepsy and epileptic seizures" (Fisher et al. 2017). Moreover, it is assumed that the patient has already been diagnosed with an epileptic seizure.

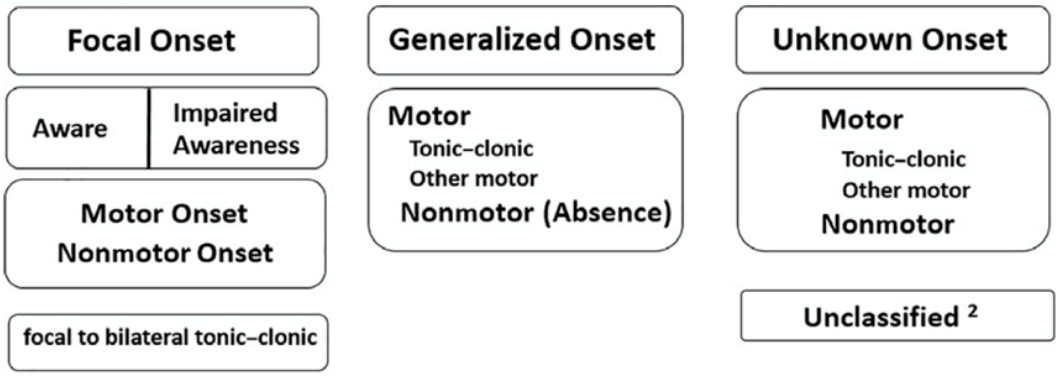
Figure 1 – ILAE classification of epilepsy and epileptic seizures



Resource: Scheffer et al. 2017, p. 515.

Seizure type is set on the first level as it can be impossible to determine the type of epilepsy, and the seizure type is the most completed diagnosis. The classification of seizures according to ILAE can be displayed in basic and expanded version (Figure 2). For the further explanation, the basic version will be presented. Moreover, without detailed medical history from a practitioner or neurologist, the precise definition of the seizure type from a respondent will be rather a complex issue.

Figure 2 – ILAE classification of epileptic seizure types, basic version



Resource: Fisher et al. 2017, p. 524.

Furthermore, the second level consists of epilepsy type, and the third level consists of epilepsy syndromes. It is crucial to note that ILEA do not have any approved epilepsy syndromes. Epilepsy can be also defined through its etiology that is presented in Figure 1. Moreover, this classification involves comorbidities as a part of epilepsy as a disease, which is an important issue that was not addressed in some early epilepsy studies (for instance, Kugoh 1998; Jacoby et al. 1993).

2.2. Epidemiology of epilepsy

It was proposed by various studies (for instance, Gaitatzis et al. 2004; Sridharan, Murthy 1999) that epilepsy has no strong correlations with age and geographical locations. Even though some studies (for instance, Sridharan, Murthy 1999; Hermann 1992) implies no impact of socioeconomic and geographical location factors on the prevalence of epilepsy, there are some inconsistent scientific arguments. Those various studies can be a result of the Global Campaign Against Epilepsy initiated by the WHO that was endeavoured for the destigmatization of the disease around the world. Nevertheless, some geographical and socioeconomic patterns are not addressed in the majority of studies, and according to Tlusta et al. (2009) there is a need of a further and deeper exploration.

2.3. Health-related quality of life and health status

Despite the notion that the concept of quality of life is a broader and more complex, some researchers (Wijnen et al. 2018; Santos et al. 2018; Friedman, Islam, Ettinger 2013) tend to apply a narrower concept like health-related quality of life or health status. The former is limited by defining the quality of life based on physical and emotional functioning. On the other hand, the latter is related to the list of pre-defined factors. Both of those concepts are related to the quality of life to some extent (Hermann1992).

However, for this thesis, it is essential to differentiate those concepts due to its complexity. Health-related quality of life and health status are included in the concept of the quality of life as it contains physical and emotional statuses along with factors regarding their health factors as

a result of an illness. To assess the complex model of QoL in PWE, the distinctions between these concepts should be made.

2.4. The concept of quality of life

One of the main focuses of this thesis is the concept of the QoL that is embedded in the majority of the surveys and studies like QOLIE (Quality of Life in Epilepsy inventory) or ESPERA study (European observational Study on Epileptic Patients Requiring at least two Antiepileptic drugs). According to Tupper et al. (1990) quality of life can be explained as "the experiences, behaviour, and status of groups of individuals known to be suffering from an illness". The significance of this concept can be explained by the growing interest in improving patient care to improve health status. Moreover, it can be used in clinical trials to compare and differentiate results (Hermann 1992, p. 154).

The issue of measurement of the QoL is central to this thesis as it provides a theoretical background of the possible measurement of this concept through qualitative approaches. The main reason is to identify significant dimensions and factors that should be included in the QoL assessment in both qualitative and quantitative methodologies. The dichotomy of QoL is based on the distinction between generic versus specific assessment (Hermann 1992).

In the case of the generic assessment, the main idea lies in creating health profiles of utility measures. Health profiles are defined as single tests or instruments for the specific scales and, at the same time, can include more than one test. For instance, in PWE health profiles can be created in case of a series of tests that can define the level of depression, anxiety or mood disorders. There exist generic health profiles that can be used in various studies. QOLIE can be used as one of them due to its comparative nature and applicability in many countries (Czechia, Korea, USA, UK). On the other hand, there are utility measures that are unidimensional and can be expressed as an index/scale (Hermann 1992).

The disease-specific assessment is concentrated on one distinct condition and is limited by the one-sided vision of the QoL. As a result, this kind of measurements can be challenging to apply in comparative studies regarding more than one disease. At the same time, this measurement has the potential for the deeper exploration of the QoL for the particular condition. There can be anticipated a more detailed vision of the factors that can influence the QoL.

2.5. Instruments of assessing quality of life

Various instruments can be used in the assessment of the general QoL and QoL in PWE. Their use depends on many factors. Nevertheless, the most common QoL instrument that is used in the epilepsy studies is Quality of Life in Epilepsy inventory that can be used in three variations - 10, 31 or 89-item version. QOLIE-89 is considered to be the original inventory that is created with a purpose for the measurement of the QoL in epilepsy (RAND © 1994). QOLIE-31 is the short version of this inventory that is used quite often in a complex with other questionnaires. QOLIE-10 is a short version of the 31 version and can be filled by the patient

him/herself (Cramer et al. 2000). All three versions are self-administered and have their own scoring manual.

In attempt to understand the contribution of the qualitative approach that is used in this paper, I would like to present in this section several quantitative instruments of assessing QoL among PWE. The generated semi-structured questionnaire, which will be later presented in the methodology section of this thesis, was based on the influential factors' classification that was used in these instruments. In addition to that, these instruments are one of the most used for the QoL assessments in PWE.

2.5.1. Disease-specific instruments

The study by Saadi et al. (2016) in Bhutan were aimed to measure the QoL in PWE with QOLIE-31. The findings revealed the low score in PWE with a difference between male and female patients. Moreover, gender differences were in the level of the fatigue/energy and cognitive functions subscales. In the detailed perspective the poor QOLIE score was determined by the low level of education, young age and, at the same time, increases perceived stigma by PWE. Furthermore, the question concerning driving were removed from the instrument as there is no restrictions in driving in the country where the study was conducted. The difference situation can be seen in Czechia, which was discussed in the chapter 4.

Nevertheless, in recent years there are new attempts to create a distinct instrument for the QoL assessment specifically in PWE. According to Jehi et al. (2011), there is a demand for a new instrument that is not focused exceptionally on the seizure severity and frequency, but also on other dimensions. The treatment plan is highly dependent on those two criteria in epilepsy treatment. On the other hand, they cannot be used as a reference frame for the QoL status.

2.5.2. Knowledge Program instrument

One of the new instruments that were used in the cross-sectional study in the USA is a Knowledge Program. The study was based on the Cleveland Clinic Epilepsy Centre, where the new instrument was applied in the data collecting process. The Knowledge Program is determined to assess the concept of QoL in PWE as a complex and multidimensional model. The program contains several scales and inventories that can, according to the authors of the study, explore the issue on a deeper and more complex level. The QoL is assessed with the help of QOLIE-10, the seizure severity was evaluated by the Liverpool Seizure Severity Scale (LSSS), depressive symptoms by the Patient Health Questionnaire version 9 (PHQ-9). Moreover, there was the assessment of the overall psychosocial functions including employment status and driving (Jehi et al. 2011, p.724).

The findings of this study confirm the multidimensional nature of the QoL in PWE. Furthermore, the authors state that there are some visible benefits from using an electronic method in collecting data as a patient was given the electronic tablets with questionnaires during the waiting time in the practitioner's office. Nevertheless, findings suggest that several factors can affect the QoL of the person with epilepsy, and the treatment plan should not concentrate only on frequency and severity of seizures (Jehi et al. 2011, p.725). Results of the study using the Knowledge Program instrument shows following significant factors of QoL in PWE: driving,

work, and marital statuses, seizure severity, number of antiepileptic medications, and depression (Jehi et al. 2011, p.724).

2.5.3. Epi-Qol

Piazzini et al. (2008) used a different instrument in assessing the QoL in PWE from 24 secondary and tertiary Italian centres for epilepsy care. The Epi-Qol is a self-administered 46-items questionnaire that is based on the QOLIE-31 and as a measurement scale uses a Likert scale format from 1 "'very frequently" to 6 "not at all". The Epi-Qol instrument was generated to explore the six following domains: physical functioning, cognitive functioning, emotional well-being, social functioning, seizure worry, and medication effects. Those domains are suggested to be valuable for the people diagnosed with epilepsy. The goal was to evaluate the new instrument that contains psychometric properties and therefore explore the main affecting factors in the total health-related quality of life (HRQOL). In this study, it is crucial to understand that the meaning of the QoL and HRQOL are swapped. Therefore, what is defined in this thesis as QoL, was used in the study by Piazzini et al. (2008) as HRQOL. This particular instrument revealed that the seizure frequency has the strongest influence on the QoL. At the same time, it was confirmed that the Epi-Qol is a valid and reliable instrument especially for the psychometric functioning in PWE.

2.5.4. Psychiatric instruments

There are some concerns regarding the psychiatric comorbidities in PWE that can be omitted in the general health profiles or in instruments that are focused primarily on the effect of the clinical nature of epilepsy. Kováts et al. (2017) in the Hungarian study were examined four following psychiatric instruments: The World Health Organization Quality of Life Inventory version 5 (WHOQOL-5), Diener Satisfaction with Life Scale (SwLS), QOLIE-31 and Illness Perception Questionnaire (IPQ). This cross-sectional study was focused on the 19 factors that can influence the QoL in 170 PWE located in Budapest, Hungary. Authors suggested that each of the selected instruments can be tied to specific characteristics and, therefore, affect the results regarding QoL. Also, they hypothesized that those factors can significantly alter the perception of the studied disease (Kováts et al. 2017).

It was founded that WHOQOL-5 is highly associated with indicators of general health including the level of the anxiety and depression (Kováts et al. 2017). That means that the health status of the patients can play a significant role in the QoL in this particular instrument and only partially affected by the experienced anxiety and depression. It is important to note that in recent years there is an increasing number of studies that confirms the significance of the mental health in the treatment plan for the various diseases. Epilepsy as a chronic condition can have a considerable effect on the life of the diagnosed person and, therefore, affect his/her QoL.

Nevertheless, the SwLS scores are considered to be linked to the demographic, health and treatment-related factors. Interestingly, none of those factors include those that can be tied to epilepsy as a health condition. Even though this instrument can be used in the evaluation of life satisfaction, it can be quite difficult to apply in the QoL assessment among PWE. At the same

time, this instrument contains 5 items that concern global cognitive judgments of life satisfaction (Diener et al. 1985).

The QOLIE-31 scores in this same study were founded to be predicted mostly by the health-related factors regarding disease-specific indicators in epilepsy. In this study was used the previously validated version of the questionnaire in Hungary. On the other hand, the IPQ score was affected by education and health-related factors. Interestingly, these two instruments showed the significant effect of sleeping disorders, depression, anxiety and the number of AEDs on the overall scores (Kováts et al. 2017, p. 54). Moreover, this was the first time the IPQ was used in the epilepsy research, and authors state that despite some availability issues, this instrument has potential for the discovering subjective perception of the PWE (Kováts et al. 2017, p. 57).

Taken together, the epilepsy as a chronic neurological disease that is characterized by various types of the epileptic seizures should be considered in the context of the QoL concept. This is essentially due to the fact that based on the various quantitative instruments of the QoL assessment, the results show that there are several potential factors based on the nature of the disease that impact QoL among PWE.

Chapter 3

3. Topic of quality of life in epilepsy

QoL in PWE has its specific traits that should be acknowledged during the QoL examination. Nevertheless, it also should be noted that epilepsy, as a neurological disease, is not a modern phenomenon and, consequently, the QoL for people with diagnosed epilepsy already has been examined. Nevertheless, I would like to stress that there are several models of the QoL evaluation in epilepsy, some of which will be presented in this part of the thesis. Moreover, as one of the aims of this thesis is the establishment of the influential factors of the QoL among female PWE, it essential to look into already defined factors and their classification in several studies.

3.1. The model of quality of life in epilepsy

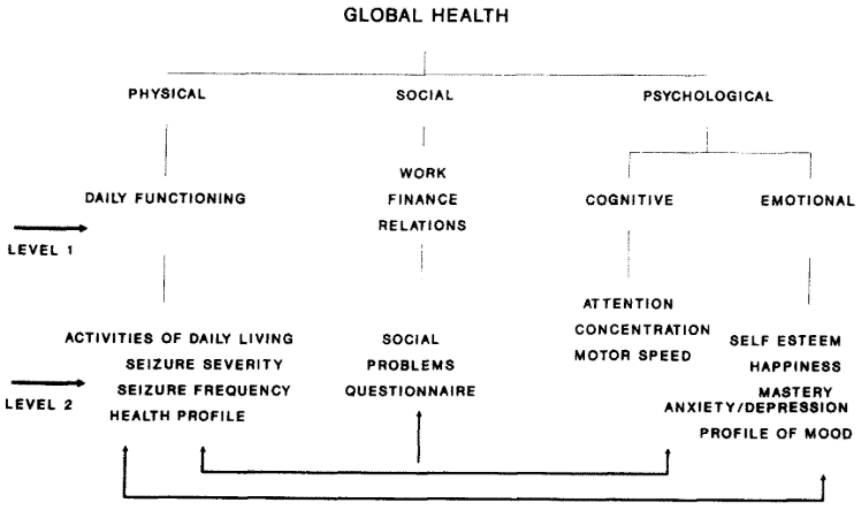
There are several models of the QoL in epilepsy that were conducted based on different studies. It is crucial to note that each of the presented models in this thesis was used as a reference point for a thorough understanding of the possible issues in QoL among PWE. Even though there has been a considerable amount of studies on testing different scales for measuring QoL in epilepsy (Cramer et al. 2000; Jehi et al. 2011; Piazzini et al. 2008), there are a few studies that suggest a concrete model for assessing the QoL in epilepsy. Hence, in comparison with QoL in gastric cancer (Lee, Lim 2019) or schizophrenia (van Rooijen et al. 2019), there are several models of assessing epilepsy. In this part of the thesis, I would like to present three exact models of QoL in epilepsy based on the particular studies - one in the global perspective and two with a greater concern to the mental health of PWE.

3.1.1. Global perspective on the quality of life in epilepsy

Understanding epilepsy in the global sense can address the most vulnerable aspects of the health among PWE and, therefore, their needs to improve their QoL. Figure 3 shows the health-related

quality of life for PWE based on Meenan and WHO definition of health that was used in the qualitative study by Baker et al. (1993). According to this model, epilepsy as an illness affects the health on two levels. The first level is connected to the daily functioning form a physical aspect. Later it affects the social aspect of work, finance, and relations. After that, the psychological aspect is influenced both in a cognitive and emotional sense. On the second level, several particular daily activities affect the health of PWE.

Figure 3 – Health-related QoL for PWE



Resource: Baker et al. 1993, p. 524.

This perspective suggests that from the physical aspect the most crucial characteristics that interfere with health are seizure severity and frequency along with comorbidities that are part of the health profile. Then there are social problems that were presented by the 51 % participated patients in the study by Baker et al. (1993) are illustrated in the social isolation of the National Health Plan (NHP). Moreover, there are some concerning evidences about concentration and motor speed that was proven to be a problem in the various studies (Siarava et al. 2019; Bishop, Allen 2003) including children patients with epilepsy (Elliott, Lach, Smith 2005). After that, there are psychological comorbidities such as anxiety and depression, low self-evaluation of happiness and low self-esteem. The effect of the psychological comorbidities will be addressed in the next subchapter in a more detailed way.

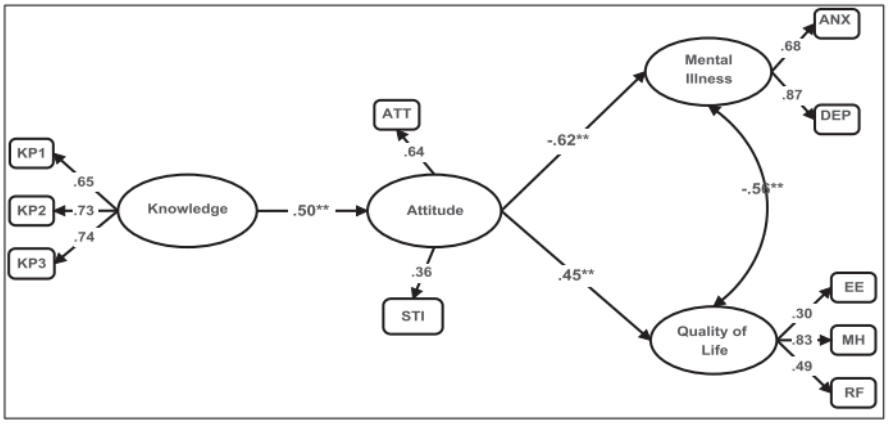
This model proves the initial idea of this thesis - the QoL in PWE is affected by the disease to some extent. Even though there are few actual models of the QoL in PWE, this one presents the epilepsy relation to the WHO definition of health. Furthermore, affected QoL has a significant effect on their health in the future, relationships and ability to integrate back to society as the social isolation scale showed high scores for half of the participants of the presented study. Moreover, this model illustrates the significance of the mental in PWE that is addressed in the next subchapter.

3.1.2. Mental health model in epilepsy

Several studies show the importance of mental health in assessing the QoL in PWE. The psychological issues can be presented as a comorbidity with relation to the AED or as

a pre-existed one. In the case of the presented case studies and models here, there will be used psychological issues as comorbidities. The study by Yeni et al. (2018) is focused upon a basic model of QoL and after the measurement by the Epilepsy Knowledge Scale, Epilepsy Attitude Scale, Stigma Scale, HADS (Hospital Anxiety and Depression Scale) and QOLIE-10 were adjusted with corresponding findings. Figure 4 presents the final version of the model in this study that was conducted in Turkey.

Figure 4 – Health mental model in epilepsy



Resource: Yeni et al. 2018, p. 216.

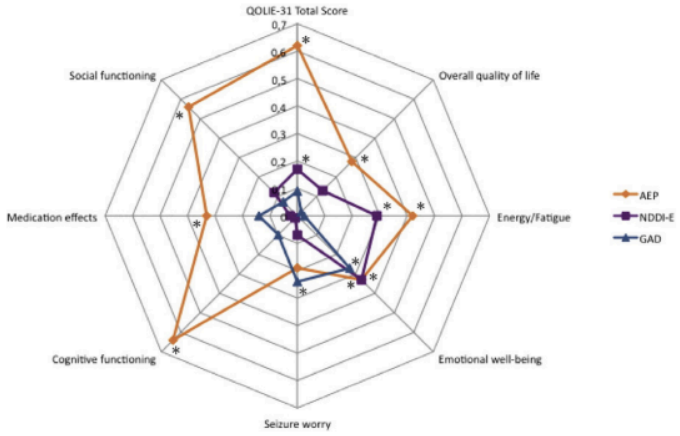
It demonstrates that knowledge about the condition itself had a great effect on the personal perception of the disease and stigma for the PWE. This shows that it is probable that even a PWE does not obtain sufficient information about the condition that can be the reason for a more negative attitude in comparison with PWE with basic knowledge. Furthermore, negative attitudes and existing stigma in epilepsy was found to be a predictor of mental health status with a negative effect. In addition to that, a high level of the perceived stigma can be seen in patients with a worse coping mechanism due to a disease (for instance, high seizure frequency, drug-resistant epilepsy). Overall, this study states that in this model of QoL the knowledge, attitude and perceived stigma were accountable for 39 % of the variance in mental health issues, such as anxiety and depression.

3.1.3. Mental health and the influence of anti-epileptic drug in epilepsy model

The study by Micoulaud-Franchì et al. (2017) that was mentioned above shows the correlation between mental health, which are in this particular case depression and anxiety symptoms, and the AED effects. Regression coefficients of several scales were used to compose the regression model presented in Figure 5. The purpose of this study was to use Neurological Disorders Depression Inventory for Epilepsy (NDDI-E), General Anxiety Disorder, version 7, (GAD-7), Adverse Event Profile (AEP) and QOLIE-31 scales. In the model earlier there were total scores conducted multivariate regression analysis with QoL factors. There were discovered gender differences in seizure worry, energy fatigue and medication effects that suggested that those factors have a greater effect on the QoL in female than in male patients. Furthermore, this model proves the significance of the depression and anxiety symptoms in measuring QoL in PWE. In addition to that, it suggests the negative effect of the interconnection of Major Depressive

Disorder (MDD) and GAD on QoL that is stronger in its coexistance than in assessments of those factors separately.

Figure 5 – Mental health and the influence of AED in epilepsy



Resource: Micoulaud-Franchì et al. 2017, p. 22.

Furthermore, the cross-sectional study that was administered in India by George, Kulkarni, Sarma (2015) implies that several distinct factors affect QoL in PWE including AED. These factors, according to the findings through the QOLIE-10 instrument, propose that adverse effects of the AED were associated with the lowest QOLIE scores in this study. The most common adverse effects were reportedly mood changes, depression, and anxiety disorders, which suggest the association between mental health and the use of AED that in combination may be an influential factor affecting QoL in PWE. Besides, increased seizure frequency and the increasing number of AEDs may also suggest the low QOLIE score. Nevertheless, there were not found any distinct differences in a type of AED therapy. Moreover, there was no correlation between demographic characteristics and the QOLIE score. In brief, this study illustrates that AED has an effect on the QoL in PWE particularly in mental health as one of the adverse effects, which is in most cases is depression.

The evidence presented thus far supports the complexity and significance of QoL in the epilepsy model not only for the understanding the issue, but also for the future studies. These cases represent the necessity for a deeper investigation of the QoL in epilepsy regarding mental health issues. On the other hand, it is crucial to note that any of the presented in this chapter models were not a part of the studies administered in the Czechia. Taking this in mind, there is a need for a more extensive investigation of the QoL in epilepsy among Czech PWE as there cannot be found any existing models of the QoL in epilepsy in Czechia. Nevertheless, models of QoL that are presented in this section are used as an argumentation for the use of particular questions in the questionnaire and as a guideline for the deeper investigation of the problematics in epilepsy research that will be described later in the methodology section of this thesis.

3.2. Factors of quality of life in people with epilepsy

As was previously discussed, the QoL is a multidimensional concept that can be affected by distinct areas depending on the sample, living conditions or cultural specifics. However, regarding

QoL in epilepsy, the nature of the condition should be considered at first. In this section, I would like to highlight a qualitative study by Bishop and Allen (2003) that was conducted in the USA and was aimed to identify the main domains of QoL in PWE. The open-ended survey was administered in this community-based study. With the help of an open-coded method of analysis, there were revealed several findings that can be obtained mostly by qualitative research. It was found out that the QoL in PWE affects not only the intrapersonal domain but also the interpersonal and extrapersonal ones. Social support, self-concept, mental health, work and productivity, physical health, security, autonomy/independence, and family support were defined as principal domains of the QoL. As contributors to the better QoL were recognized family and other social support, religion/spirituality, leisure activities, having basic needs met, good mental health, and employment. On the other hand, psychological distress, transportation limitations, stigma or perceived stigma, seizures and seizure worry, and cognitive limitations were viewed as factors that worsen QoL among PWE in the USA (ibid). In brief, this study revealed not only the complexity of the QoL but at the same time the more profound nature of the qualitative methods in the epilepsy research.

Another approach was used in the Russian study by Melikyan et al. (2012). Socio-demographic and clinical factors were chosen as principal. It was revealed that seizure frequency, age, and depression were showing a negative effect on the QOLIE score. It is important to note that even authors of the study highlight the importance of the cultural context of this study as the comparison with other similar studies showed that Russian respondents were showing low overall HRQOL scores, particularly in emotional well-being, cognitive and social functioning subscales. For the PWE in Russia depressive symptoms were affecting the overall QoL the most. As for the cultural context, there is a possible explanation in the value of the frequency of seizures, which is in more than 40 % of PWE in Russia reported "12 and more per year" (ibid). Another study from the USA by Friedman, Islam, Ettinger (2013) revealed that the type and nature of epilepsy was responsible for the low score in QoL. Those patients are prone to suffer from depression and seizure worry that, at the same time, is responsible for the decrease in overall QoL (ibid).

The study by Saadi et al. (2016) in Bhutan suggested that there is an impact on QoL in education, wealth, demographic and clinical characteristics. The QOLIE-31 showed that there is a difference between female and male with epilepsy. In a detailed view, there are discrepancies by sex in the energy/fatigue and cognitive functions subscales, where women were having a stronger impact on their QoL in comparison with men regarding these factors. The low QOLIE score can be predicted also by low education, a young age, and the increased perceived stigma. At this point, it is essential to note that the cultural context of the studied population can have a significant effect on the findings. For instance, driving is a significant domain, and its absence in PWE can be perceived as a limitation of personal freedom in the Czech context.

Nevertheless, it seems that each study is trying to identify the effect of the socio-demographic and clinical factors on the QoL in PWE in each country. Even though several domains of the QoL in PWE can be seen repeatedly in each study, there is a slightly different outcome for each studied population based on the culture, education level, health policy and services, and the overall health

situation in the particular country. In summary, there are several factors that may have an impact on the QoL that are specific for the PWE.

3.2.1. Gender

Gender is considered as one of the principal indicators of QoL that is tested in epidemiological studies regarding such neurological conditions as Alzheimer's disease (Podcasy, Epperson 2016), Parkinson's disease (Shulman 2007) and glioblastomas (Tian et al. 2018). The corresponding pattern can be observed in the research among QoL in PWE. In this section, I would like to elaborate on several studies and what is already known about the role of the gender in the QoL, and if it can be considered as a main influencing factor in qualitative research.

The study conducted in China by Yue et al. (2011) was aimed, using several quantitative tools as QOLIE-31, Hamilton Depression Rating Scale (HAMD), Sport Anxiety Scale (SAS) and AEP, to explore gender differences among PWE. It revealed that there are no significant differences in overall scores between male and female respondents. In addition to that, one of the findings suggests that QoL in male PWE is associated with depression and anxiety. On the other hand, QoL among female PWE is affected predominantly by the side effects of AEDs and the number of prescribed AEDs (ibid).

A Canadian study by Elliott, Mares (2012) was using data from a cross-sectional CCHS study and was also determined to test gender differences in QoL among PWE. The study was based on the assumption that the biopsychosocial model can explain QoL in PWE in a more profound way than the traditional biomedical perspective. The findings of this particular study were confirmed and compared with a non-epileptic control group. The main result of this study revealed that there is no significant difference in QoL between male and female respondents. In addition to that, there was a slight difference in PWE – it can be suggested that male respondents are prone to have fewer impairments after the epilepsy diagnosis has been made than female respondents (Elliott, Mares 2012). Nevertheless, the authors do not give a possible explanation for such a finding.

Another study by Bala et al. (2016) was aimed to assess QoL in female and male PWE with drug-resistant epilepsy. It is essential to bear in mind that in this thesis there will be no respondents with this kind of epilepsy due to rareness of the diagnosis (Kalilani et al. 2018). This particular study was conducted in Poland. The main distinction was in the depression subscale, where women were having higher scores than men, even though the depression itself did not reveal any significant effect on the QoL in female respondents. On the other hand, the depression was having an impact on the QoL among male PWE, particularly on the total QoL score, energy/fatigue, and emotional well-being subscales. Besides, the existence of the depression in female PWE affected the following subscales: energy/fatigue and emotional well-being. As for the overall gender differences, there was not any difference in the QoL among PWE (Bala et al. 2016).

The study conducted in India by Jadhav et al. (2013) was assessing the HRQOL in PWE using numerous translations of QOLIE-31. The Hindi and Marathi translations were validated for this particular study. As for gender differences, it was revealed that women were having higher QOLIE-31 scores than male respondents and non-respondents. Nonetheless, with a small sample size of 80 patients, caution must be applied, as the findings might not be as reliable as in

previously mentioned studies. Nonetheless, it is still crucial to explain that even in this study there was a gender difference in PWE with the poorest score in PWE between 19 and 24 years old (Jadhav et al. 2013).

To sum up, these results suggest that gender cannot be perceived as the indicator of the QoL among PWE. Nevertheless, there still can be slight distinctions in smaller subscales that can show some crucial insights into the complexity of the QoL factors in PWE. However, I will not concentrate specifically on the gender differences in this thesis. Taken together, these results provide crucial information about the gender differences in the mental health of the PWE in several studies and possible relation to the usage of AEDs.

3.2.2. Clinical factors

Epilepsy is a brain disease that was previously discussed in chapter 2.1. *Epilepsy and epileptic seizures* have their own specific characteristics that to some extent define the QoL in PWE. Due to the nature of epilepsy, the clinical factors should be considered. Clinical factors are here presented as aspects of the everyday life that are interconnected with epilepsy and its presentation – i.e. epileptic seizures or AED. One of the main concerns in epilepsy research is the issue of seizure severity and seizure frequency (Quigg et al. 2016; McLaughlin, Pachana, Mcfarland 2008). There is a wide-spread thought that these two factors may affect the QoL at most of the patients. The study conducted in Uganda by Kaddumukasa et al. (2019) was aimed to explore the impact of seizure severity on QoL by using QOLIE-31 and The Chalfont Seizure Severity Scale. One of the findings revealed the existence of the relationship between QoL and seizure severity. For purposes of this thesis, the main result of this study lies in fact, that there was reported an increase in the seizure severity that led to the decrease of the overall QoL score in PWE. Moreover, the seizure severity was associated with the increase of seizure worry, emotional well-being, energy fatigue, and social function. As possible comorbidities of the seizure severity were defined a social avoidant behaviour and the high risk of suffering from depression and anxiety. This issue was discussed in detail earlier in the chapter 3.1.2 and 3.1.3.

On the other hand, there is a qualitative study by Petersen et al. 2004 that was aimed at children and teenage PWE in Canada. Semi-structured and open-ended interviews revealed that there are four main domains of the HRQOL in adolescent PWE - physical, emotional/behavioural, social and cognitive/academic. The physical domain is the central concern for this section. It was reported that fatigue, sleep disturbances, and anergia/inertia are the foremost factors the physical impact of epilepsy on HRQOL. Furthermore, Gutter et al. (2019) has argued about sleep disturbance among PWE in a cross-sectional study among adult PWE. By using several instruments such as The Groningen Sleep Quality Scale, The Medical Outcomes Study-Sleep, The Sleep Diagnosis List, The Epworth Sleepiness Scale, The 36-Item Short-Form Health Survey (version 2), it was confirmed that PWE is more regularly affected by disturbed sleep than the control group. For instance, the Sleep Diagnosis List (SDL) tool shows that PWE scored more than 60 % than in the control group. Nevertheless, the multivariate analysis used in this study suggests that sleep disturbances can be caused by cardiovascular problems, to which in combination with pulmonary disease, PWE are inclined to. To sum up, sleep disturbances can be

seen as a clinical factor that has an impact on the QoL in PWE, but at the same time, it should be noted that it can be a part of such comorbidities as cardiovascular problems or AEDs' side effect.

Even though it was discussed beforehand in this thesis, that the issue of acquired epilepsy due to head trauma or surgery will not be discussed, the Chinese study by Liu et al. (2011) illustrates the predictors of QoL among PWE with post-traumatic epilepsy. It is crucial to bear in mind that this type of epilepsy can have specific characteristics in comparison with the most common generalized or focal epilepsy. The predictors were tested by such tools as QOLIE-31, Sheehan Disability Scale (SDS), and SAS. The most influential factors of the QoL were anxiety, therapeutic compliance, depression, the severity of the seizure. Besides, it was revealed that site of trauma and the severity of trauma were also considered as an influential factor, although they did not have such strong effect as the ones mentioned earlier. As this study shows, the specific characteristic of this type of epilepsy has an impact on the QoL. Nevertheless, this impact is still weaker than psychological and mental problems of PWE, which are seen in similar studies as presented here (for instance, Yeni et al. 2018; Hoyos et al. 2017).

Furthermore, there is a tendency to explore how the particular medication can affect the QoL (Takahashi et al. 2019; Tabrizi et al. 2019). One such study is a Lymphangioleiomyomatosis (LAM) study that was conducted in Spain by Alfaro et al. (2019). The aim was to explore and evaluate the effect of the lacosamide on QoL among PWE and their behaviour. The study lasted one year and was carried out in 11 hospitals. One of the limitations of this study was the focus on the focal epilepsy treatments. Nevertheless, the effect was measured by such tools as QOLIE-10, The Hospital Anxiety and Depression Scale (HADS) and the Barratt Impulsiveness Scale (BIS). The findings showed that lacosamide may provide a better QoL among PWE with the exception in the BIS if the initial scoring in QoL was poor. It is crucial to point out that this may be a result of the confounding with seizure control. Moreover, the lacosamide did not show the increase in the new psychological comorbidities and, therefore, excluded this AED's side effect in the mental health, which, as was discussed earlier, are common comorbidities in PWE.

After all, not only psychological comorbidities can be counted as clinical factors that have an impact on the QoL in PWE. One of the qualitative studies by Collard, Marlow (2016) was aimed on assessing how exercise can affect the QoL in PWE. It is surely not the traditional way of assessing the QoL in PWE in comparison with previously presented studies in this thesis. Nevertheless, this study illustrates that epilepsy itself puts a considerable amount of pressure on every decision that is made to improve QoL. The narrative analysis revealed that physical exercising for one year provided PWE with an increase in confidence, self-esteem, self-efficacy, relaxation, and improvement of the overall mental state. On the other hand, some PWE reported that exercising could bring them and other members of society in danger. Paradoxically, epilepsy itself was a reason due to which PWE could not improve their QoL by exercising. I would like to note that exercising as a physical activity can be hardly understood as a clinical factor for PWE. However, the issue of sport among PWE has not been examined thoroughly in order to exclude this factor as a potential influence on the QoL.

Clinical factors of the QoL among PWE can be presented by the seizure frequency and severity that are characteristic for the particular type of epilepsy. These two factors are considered to be fundamental due to the nature of epilepsy as both of them has an impact on the daily routine

and everyday activities. Furthermore, the physical condition such as sleep disturbances, cognitive dysfunctions or fatigue is crucial for the QoL. In addition to that, AEDs affects the QoL to the particular extent. Mainly in the context of the side effects and an impact on the physical and mental well-being.

3.2.3. Psychological factors

Throughout this thesis, the issue of the psychological factors corresponding with QoL among PWE was mentioned in the complex model of QoL among PWE and in the connection to the AED's adverse effects. Nevertheless, mental health issues can be considered as an influential factor for PWE. In this section, I would like to elaborate on this issue based on the epilepsy research in QoL assessment. Moreover, it is crucial to understand that psychological factors cannot be considered only as comorbidity, but also as an adverse effect of the prescribed medication as a part of the treatment.

The prevalence of depressive symptoms and their impact on quality of life in patients with drug resistant focal epilepsy (IMDYVA) study was aimed to explore the prevalence of particular depressive symptoms in PWE with Drug Resistant Epilepsy (DRE) and PWE with controlled focal epilepsy (Garcia, Garcia-Morales, Gil-Nagel 2015). For the assessment of the depressive symptoms, the Montgomery-Åsberg Depression Rating Scale (MADRS) and BDI-II were used, and for the QoL assessment was applied QOLIE-31. The findings revealed that the most substantial impact occurred in depressive symptoms that were not treated. The prevalence rate for those symptoms was approximately 50 %, but only 15,9 % were diagnosed before this study. The Greek study by Siarava et al. (2019) had a slightly similar aim, but with the use of a control group without epilepsy. The depression score was evaluated by the Patient Health Questionnaire version 9 (PHQ-9), while the QoL was calculated with the use of World Health Organization Quality of Life Instruments (WHOQOL-BREF). The central findings of this study demonstrated that there can be a correlation with the use of AEDs. In other words, AEDs can have an influence on the incidence of depression among PWE. Furthermore, in this study major depressive disorder was considered to affect one in four PWE. To sum up, the depression and depressive symptoms can be counted as a major psychological factor for the evaluation of the QoL in PWE and, consequently, this should be reflected in the interviews.

The Multicenter Trial of Epilepsy and Psychiatric Diseases (MEPSY) study by Lee et al. (2014) was conducted in Korea. The PWE in this study were examined for depression, anxiety, suicidality, and also for the burden of the adverse effects of AEDs and the overall QoL. For these purposes was used several tools - Korean version of the NDDI-E (PWE-K-NDDI-E), the GAD-7, Liverpool Adverse Events Profile (K-LAEP), QOLIE-10. It was found that the strongest predictors of QoL among PWE were the adverse effects of AED. That issue was already discussed in chapter 3.1.3. As the influential factors were also recognized as depression, seizure control, anxiety, and household income. Seizure control and seizure frequency significance were already discussed in the previous subchapter. The economic factors of the disease will be examined later in this thesis. As for the depression and anxiety, the authors discovered an indirect effect of the anxiety on the QoL through adverse effects of AEDs. Nevertheless, it can be seen that depression as a psychological factor plays a significant role itself without being a possible adverse effect of

the prescribed medications. Furthermore, Tedrus, Sterca, Pereira (2017) focused on evaluating not only depression itself among PWE but also the influence of the physical activity. The effect of exercising on the overall QoL was presented in the chapter on Clinical factors with a greater effect on the increasing the QoL itself than on the decreasing comorbidities of epilepsy. This study has revealed that a sedentary lifestyle, that is typical for the PWE, can predict a lower QoL and a high level of perceived stigma. On the other hand, PWE that was involved in a more regular physical activity has shown a higher QoL and, accordingly, a lower risk of psychological comorbidities. Nevertheless, it is necessary to note that physical activity can be refused due to the potential threat for the PWE and other participants of this particular physical activity nearby.

There was an Argentinian study by Scévola et al. (2017) that had implemented depression as a comorbid factor for the PWE and its relationship with QoL. The Structured Clinical Interview for Axis I diagnoses of Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), the BDI and Quality of Life Enjoyment and Satisfaction Questionnaire short form (Q-LES-Q-SF) was adopted to evaluate this relationship. It was revealed that there is a significant negative correlation between the severity of depression and QoL. Participants with depression were linked with poor health perception and the lower QoL score. In this study, it was also proposed that depression can be associated with the adverse effect of the AEDs. The study by Agrawal et al. (2016) was using various instruments to accurately evaluate the connection between depression and QoL in PWE. The following instruments were applied in this study - the BDI-II, HADS, NDDI-E, the Emotional Thermometer (ET7) and the Major Depression Inventory (MDI), and for the QoL assessment - EQ-5D-3L instrument, which is a combination of the European QoL Visual Analogue scale (EQ-VAS) and the European QoL 5 Dimension scale (EQ-5D). The central results suggest that there is a correlation between QoL and depression regarding the adopted instruments. Furthermore, in 43,9 % of the studied PWE was founded major depression, which confirms the importance of the phycological factors for the QoL assessment.

As was previously explained, the main and the most discussed psychological factor among PWE with the strongest effect on the QoL is the depression or depressive symptoms. Regarding this fact, the interview and further discussion should take this into account. Furthermore, psychological factors can be manifested among PWE as an adverse effect of the prescribed medication or as a comorbidity of the condition.

3.3. Emotional burden of the epilepsy

In the previous subchapter, I was addressing the effect of the psychological factors of epilepsy on the QoL. Notwithstanding, I would like to note that as a chronic condition, epilepsy can be viewed as a significant emotional burden. It is also vital to note that in this section I would not use the concept of the Burden of Disease (Wijnen et al. 2018). Alternatively, I would like to elaborate on the issue of the emotional burden of epilepsy in the context of the QoL perception. For this thesis, it is necessary to realize how the QoL in the epilepsy is perceived in terms of emotions as the methodological approach of this thesis is qualitative. In the following discussion, I will investigate the emotions linked to the PWE in detail.

The qualitative study by Räty, Söderfeldt, Wilde Larsson (2007) was exploring the QoL in the epilepsy concept base on the Belief Desire Theory of Emotions. Researchers were collecting data by an interview method with open-ended questions and analysed using qualitative content analysis. The main findings revealed that PWE most generally expressed the feeling of confidence and, in some circumstances, hope. This feeling of hope can be a consequence of the treatment or the gain of seizure control. Anxiety, despair, and fear were considered to be negative emotions experienced by the PWE. Moreover, the study classified emotions as complex positive, and a negative one. Forbearance was recognized as a positive complex emotion. Nevertheless, it was not explained if this emotion was a result of family and social support. On the other hand, indignation, sadness, insecurity, anger, and resignation were classified as complex negative emotions. They can be a consequence of the adverse effects of AEDs, the poor social support, or limited control of the seizure frequency. Based on this study, the authors distinguished PWE into the two following groups - healthy vs. handicapped. This can be interpreted as a self-evaluation of PWE based on their emotions towards the condition and the QoL. These results are taken into account not only in the process of the analysis but also during the stage of gathering data.

The different qualitative study by Ring et al. (2016) was intended to find the association between a particular emotion and the QoL among PWE based on the results of the grounded theory analysis. Moreover, the aim was to discover how the PWE perceive their QoL, and what meaning they put in this concept. It was revealed, that the main impact on resilience was due to socio-environmental influences. PWE were either in a "fighting spirit" or were "finding other things to do". It was suggested that the process of reintegration is a shifting concept for the PWE and, therefore, social support is rather required for this category of patients. Based on this study, it is likely to confirm the results from the previously discussed study that PWE can be categorized into two groups - healthy and ready to fight vs. handicapped and trying to find other things to do. Nevertheless, there is a necessity to discuss the emotional burden from a rather different approach.

The emotional burden does not require to be defined solely by the self-evaluation of the PWE, but also by the society and the person's social group or community. By that, I indicate the perceived stigma and discrimination based on epilepsy as a neurological condition. A. Jacoby (2002) in his theoretical article on the stigma and epilepsy was arguing about its effect on the QoL among PWE. This work is based on Goffman's definition of stigma, where the diagnosis denial is one of its way of expression. The diagnosis denial is a simplistic denial of the condition or the belief that condition is overdramatized or is "in the head". According to the author, this stigma can be a consequence of the myths and legends associated with epilepsy as a neurological condition and, in most cases, based on its physical expressions such as seizures. Most importantly, the legislative restrictions can be also perceived partially as an expression of the stigma. As I was previously discussing this issue with regards to the driving restriction, this can be also done as a result of the public endangerment due to the uncontrollable nature of the condition. Nevertheless, there are two main dimensions of the perceived stigma in epilepsy - visibility and controllability. Those dimensions are addressed in the questions for the semi-structured interview to reveal a possible stigma experienced by respondents.

In this section, it was discussed how epilepsy can cause the emotional burden, and in which dimensions it can be more or less visible. The following discussion is a summary of the existing

studies on the emotions among PWE and its contribution to the QoL, self-evaluation, and the evaluation of the societal perception of epilepsy. Based on the results of those qualitative studies, it was possible to modify questions for the interview in a way that emotional burden will be addressed among the feeling of the perceived stigma with particular examples of those situations in the context of the existing social network.

3.4. Economic burden of the epilepsy

The economic burden of a particular disease should be taken into account as this thesis is composed from the socio-epidemiological point of view. Based on this, it should be additionally noted that the economic burden of epilepsy is a fairly flexible concept as the treatment and diagnosis process of epilepsy changes based on the type of epilepsy and epileptic seizure type. Furthermore, I would like to note that the economic burden of the disease is not viewed to be a central concept of this thesis based on the previous discussion. Unfortunately, there are a few studies that were intended to explore the economic burden of epilepsy, which implies either the unpredictable nature of the condition or the lack of academic and scientific attention to improving the QoL and the financial burden for the PWE. Notwithstanding, the value of the economic burden is also reviewed in the interview as a potential variable of the QoL among PWE.

The study by Wijnen et al. (2018) was conducted in the Netherlands to evaluate the economic burden of epilepsy. The central hypothesis was implying that the certainty of the diagnosis may improve the QoL among PWE. The main reason for that hypothesis ceases in the fact that it takes up to a year to obtain a certain diagnosis of epilepsy or its absence. This longitudinal study revealed that the initial costs of the medical procedures regarding epilepsy are decreasing by up to 70 % during the first two years after the diagnosis. The healthcare costs, costs for the patient, and its family and other supplementary costs decline after 3 months after the diagnosis. This implies that the original protocol of the epilepsy diagnosis is moderately high in price or includes a significant amount of medical staff and technologies. According to the authors, the 24-hour EEG is the most costly and stressful for the PWE medical procedure. Nonetheless, this procedure is a way of the accurate diagnosis of epilepsy and properly classified epilepsy and epileptic seizure types. In this case, it is essential to note that the economic burden of the diagnosis is also connected to the emotional burden. PWE and their family are in a state of uncertainty up to the moment of the diagnosis.

The ESPERA (European observational Study in Epileptic patients Requiring at least two Antiepileptic drugs) study is centred on the QoL among PWE with DRE and also on the economic burden of epilepsy (Villanueva et al. 2013). To evaluate that concept several instruments were used such as QOLIE-31, NDDI-E, and EQ-5D-3L. The QoL based on the type of epilepsy and the instrument was presented previously, but I would like to note the PWE with DRE were suffering more frequently with depression compared with PWE with drug-responsive nature. Furthermore, they were having a significantly lower QoL score. As for the economic burden, the PWE with DRE were in a need of the more healthcare resources and, therefore, their economic burden was higher than among seizure-free PWE. This study revealed how the type of epilepsy

can be a determining factor in the economic burden assessment. Nevertheless, it was not clarified if it affected the QoL in any way.

The economic burden of epilepsy is a rather complex concept as it significantly varies based on the type of epilepsy and seizure type. Nevertheless, there is a necessity to change the healthcare cost for this condition as the diagnosis trajectory can be an emotional burden for the PWE and their family and, hence, have an impact on their QoL. Furthermore, I would like to note that it is rather difficult to make any assumptions based on the two studies that were suitable for the literature review and, consequently, the further exploration of this concept and the QoL should be made. Nevertheless, for this thesis, those two studies can be considered as valuable and enough for addressing this issue in the interview based on two questions about PWE`s overall life satisfaction and the wish to change the course of treatment.

3.5. Family and social support

I have mentioned in the previous discussions that the emotional and economic burden along with the psychological factors of the QoL in epilepsy can be affected by family and social support. QoL among PWE can be influenced by social support and the family in the context of resilience, the financial and emotional support for the PWE during medical procedures, and treatments. Moreover, social support can be viewed as valuable in overcoming the adverse effect of AEDs. In this section, I would like to explore the significance of the family and social support along with the example of the social support for the PWE in the Czech Republic.

To understand the significance of social support, it is crucial to define it. In this thesis, I would like to define social support as in the study by Charyton et al. (2009) as "the commitment, caring advice, and aid provided in personal relationships". This study was a part of the California Health Interview Survey in the USA and was aimed to explore the influence of social support on the QoL in PWE. It was discovered that the lack of this kind of support was associated with a poor QoL score. Moreover, after the comparison of PWE with a control group without epilepsy, the PWE group showed the stronger effects of the lack of social support. The main reason for the support among PWE was in the feeling of being loved and wanted. Moreover, the authors of the study suggested that in the nearest future the epilepsy treatment should include not only physicians but also social workers. In that case, it can be said that there is a strong correlation between the QoL among PWE and the social support, but I should note that the social support itself is a significant factor in the QoL even among healthy populations (Sanghera, Coast 2019). Therefore, I would like to elaborate further on the issue of family support and caregivers among PWE.

The explorative cross-sectional study by Mahrer-Imhof et al. (2013) was focused on the relationship between the family, factors of QoL in PWE, and their family members. For this study, several instruments were used - The Schedule for the Evaluation of the Individual Quality of Life-Direct Weighting (SEIQoL-DW), QOLIE-31 Version 2, The Social Support Questionnaire, Short Form-German (F-Sozu K-14), Family Adaptation and Cohesion Scales (FACES III), The Patient Assessment of Care for Chronic Conditions (PACIC), Activities of Daily Living (ADL/IADL). The fundamental result of the study implies that family support is the most influencing factor of QoL in PWE. As for the QoL of the family member, the network size of the

PWE was considered as a vital factor. Moreover, this study also proposed that there is a necessity of including more than only a specialist in the treatment process. The difference is that the authors of this study suggested that it would be relatives, who can help to slow the decline of the QoL among PWE. I would like here to note that those suggestions can modify not only based on the study but also depends on the socio-cultural background of the place, where the study was administered.

On the other hand, it is rather crucial to understand not only the significance of the family and social support for the QoL score among PWE, but also to address the actual needs of the PWE and their caregivers. The Italian study by Celani et al. (2018) explored that issue in detail. Their initial hypothesis stated that there can be different perceptions of epilepsy among PWE and their caregivers. The results revealed that 56 % of PWE were having concerns about the adverse effects of AEDs since they have been diagnosed. At the same time, caregivers were concerned with PWE employment's future and their employment status. In that case, it is plausible to establish that the initial hypothesis was confirmed as the needs and concerns of the PWE and their caregivers are distinct. I would like to highlight the fact that it is rather difficult to examine if there were no confounding and bias in this study. Nevertheless, as for the most significant and relevant needs, PWE displayed such as assistance, experience-sharing, clarity, control, and planning.

The assistance for the PWE can be understood principally by the support of family members during medical procedures and support with the transportation. The control, clarity, and planning can be referred to as the AEDs and its adverse effects, and also for the seizure control as the proper understanding of triggers and aura. The experience-sharing requirement relates to the community of the PWE that is revealed in social organizations. In the Czech Republic, there are two most common organizations that refer themselves to the bigger international community of PWE - EpiStop and Společnost E (Society E).

EpiStop is an NGO based in the Thomaeyrova`s hospital in Prague that collaborates with the ILAE and is the associate member of the International Bureau for Epilepsy (IBE). They started their work in 2007 and since then are focused on reducing the stigma and discrimination among Czech PWE. Furthermore, this organization frequently publishes professional publications regarding epilepsy – i.e. Epilepsy and employment, A woman and epilepsy. In 2018 the EpiStop organized the contest for the children with epilepsy and the modified triathlon near Prague. As for their future goals, the organization is hoping to keep promoting employment without discrimination for the PWE. Společnost E is the NGO that is community-based and is a member of the IBE and NRZP ČR (National Council of Persons with Disabilities of the Czech Republic). This organization was founded in 1990 and registered in 2014 to offer social support and "social entrepreneurship". Their project "Greenhouse" is aimed to offer a temporary job for the PWE in arranging flowers and to organize workshops for the PWE, their family members and the wider public. Moreover, they prepared a package called "Don`t be afraid of epilepsy" for the wider public including schools.

3.6. Children and quality of life in epilepsy

Epilepsy in childhood, adolescents years or young adulthood is a major topic both in neurology (for instance, Mani 2008; Rosati, De Masi, Guerrini 2015), social epidemiology (for instance, Camfield, Camfield 2015; Elliott, Lach, Smith 2005) and sociology (for instance, Carlton-Ford et al. 1995; Ziegler 1982) as it affects the primary socialization and health of the patient in early ages. Moreover, the onset age of the epilepsy is usually from 4 till 12 years and the incidence is higher than in adults (Moráň 2007, p.47). Those types of epilepsy are commonly benign and may be not visible from the outside. On the other hand, there are types of juvenile epilepsies that are drug-resistant in their nature and are characterized by high frequency of seizures and neurological deficits (Moráň, 2007 p.47).

Juvenile epilepsies and syndromes have generally the prevalence rate of $1{,}5 - 2\,\%$ in adolescents (Moráň 2007, p.49). The adolescent period is marked as one of the stressful one for the patients with epilepsy as there are certain physical and psychosocial changes that at the same time can be affected by the illness. Juvenile types of epilepsy are becoming a significant field of quality of life research as the illness can be perceived as a main barrier for socialization that is primary especially for teenagers. The Ireland qualitative study by Leahy, Hennessy, Counihan (2018) refers to such situations as "Cinderella syndrome". This kind of syndrome refers to social activities and everyday situations that are somehow restricted to an adolescent due juvenile myoclonic epilepsy (JME) that is quite common among adolescents or young adults (Leahy, Hennessy, Counihan 2018 p. 104).

For the adolescents the four following themes were revealed as having the most effect for the quality of life (Leahy, Hennessy, Counihan 2018). The alcohol consumption was a strong barrier for the PWE in adolescence as there is a strong recommendation to alcohol abstinence. At the same time, this abstinence became the source of social isolation and treatment of being "different". It is crucial to note that this kind of perception of PWE due to alcohol consumption can be distinct in other studies distinctively because of cultural and differences. The other dimension is the relationships with others and the process of making friends. The findings show that those that were having JME prior to high school were advantageous in forming new friendships (ibid). This illustrates the importance of the socialization for the PWE and their closeness with friends and family.

Furthermore, the life choices and their possible consequences were also affected by the JME (Leahy, Hennessy, Counihan 2018). In this study one of the main choices including medication and major epilepsy triggers was the loss of the driving licence. Participants perceived the loss of the driving license as the lack of freedom and the restricted lifestyle. The last-mentioned dimension affecting positively the quality of life was the education and knowledge about the condition. It affects time management that can be for the majority of the participants as a source of the parental overprotection (ibid).

Another Canadian study by Elliott, Lach, Smith (2005) was aimed to explore the young patients' view on the quality of life with epilepsy. The study used a qualitative method of semi-structured interview with grounded theory as a method of analysis. Four main domains were revealed based on the results. The physical impact on the quality of life was explained by such

symptoms as fatigue, sleep and anergia/inertia. The emotional/behavioural domain is characterised by the distress due to epilepsy. The social domain is showed as a social isolation. The last cognitive/academic domain reveals problems with learning process that can be a barrier for the growing child.

Results of those two major qualities of life studies among PWE in childhood and adolescence reveals that there are distinct problems not even in each country, but it depends on the age of the epilepsy onset and the current age of the participant. The problematics of the epilepsy among children and adolescents has a strong correlation for the possible effect on the future development of the PWE and the condition itself. In the case of this thesis, it is crucial to remember that the age of onset of epilepsy can be a major factor of the perception of quality of life. Furthermore, those specifics can be used as an explanation for the narrow definition of the participants in the practical part of this thesis.

3.7. Women with epilepsy

For this thesis, I would like to mention the distinct features of the QoL in women with epilepsy. This relates to the issues that may present in the female PWE due to biological specifics. Before exploring this issue in detail, I would like to note that the distinction between epilepsy in men and women has been already made in the studies regarding such illnesses as asthma (Zein, Erzurum 2015), depression (Noble 2005) or coronary heart diseases (Maas, Appelman 2010). However, women's health can be affected distinctly due to the hormonal changes and related to that possibility of pregnancy, which will be discussed in this thesis next.

For instance, the menstrual cycle and the overall fertility can be affected by epilepsy and AEDs at the same time (Crawford 2005). Related to the issue of reproductive health, the choice of the AEDs can be an issue regarding the use of contraception as different types of AED may contradict to some extent. In addition to the effect of medication, preconception counselling is recommended in order to evaluate the health status and the possible contradiction with AEDs during other medications and supplements during pregnancy. As for breastfeeding and motherhood, some risks are depended on the severity of the epileptic seizures and the prescribed medications. Besides, it is reported that there is an additional stress of having a seizure during some activities with a new-born child. During the menopause, the impact of the epilepsy is still present as it increases or decreases the severity and frequency of epileptic seizures based on the type of epilepsy. What is more, there are some health issues regarding bone health particularly in women with epilepsy (Crawford 2005).

If we now turn to the QoL in women with epilepsy, there is a general impression, which was mentioned earlier, that there are no significant differences in the QoL scores between female and male PWE (Bala et al. 2016). However, based on the study by Santos et al. (2018) there is a difference in comparison between male and female PWE, who are in the childbearing age. It appears that there is an overall lower score of the QoL, mostly concerning the adverse effects of AEDs and the seizure control. Therefore, there is a need for a more extensive understanding of the issue as the QoL women with epilepsy in their reproductive age can significantly vary from the QoL in men with epilepsy due to biological differences.

In summary, these results show that epilepsy should be considered as a multidimensional issue that affects QoL of the diagnosed person from various perspectives. Distinct factors should be taken into consideration during the QoL assessment such as age of the epilepsy onset, gender and others various factors that were mentioned in this particular section of the thesis. It is crucial to note that comparison between female and male PWE do not show significant results. However, the issue of the women with epilepsy itself seems to have characteristic traits that are not presented in the male PWE. Furthermore, the children with epilepsy are considered to have slightly distinct attributes of the QoL in a contrast with adult PWE.

Chapter 4

4. Quality of life studies in Czech people with epilepsy

QoL in PWE with the use of QOLIE-31 is used for validation and reliability in many countries including the Czechia. For this thesis, it is crucial to understand what was revealed in the validated studies of QoL by the specialized instruments. For instance, QOLIE-31 was tested by two studies in the Czechia (Tlusta et al. 2007; 2009). The purpose of the earlier study was aimed to test the instrument and its translation, and the last one was aimed to identify the effect of clinical and demographic characteristics on QoL. Moreover, the understanding of the perception of epilepsy in the quantitative studies in the Czechia can be used as a guide in the qualitative approach that is based upon in this thesis.

According to Tlusta et al. (2007), the QOLIE-31 as an instrument for assessing the QoL in PWE was validated and considered to be reliable for the future researches. Furthermore, it revealed an interesting controversy in an item "driving". The principal problem in 221 patients of the Neurology Clinic of the University Hospital Hradec Kralove was in answering the questions concerning the driving. QOLIE-31 is centered on several activities that can be problematical to do during the past four weeks due to epilepsy or antiepileptic drugs (AED) and it includes driving. The controversy was in the fact, that in 52 questionnaires this item was the only one, which was not filled. The further analysis revealed that after the exclusion of this one particular item, 181 questionnaires became completely answered. The significance of this item was understood in the context of the intercultural differences, particularly as driving can be perceived as a symbol of better employment and social freedom.

Moreover, there are some legal restrictions in obtaining a driving license for the PWE in the Czechia according to the legal norms for the medical fitness to drive motor vehicles in Sbírka zákonů 361/2000, part 86 (Zákony online). The norms are dependent on the numbers of epileptic seizures with further neurological deficits in the last 12 months. It is also dependant on the AED and in particular during the time of AED withdrawal or change of them. Also, the norms are

different for individual vehicles and the lorries and buses. It is crucial to understand that this decision is upon a practitioner on the demand of the PWE.

The study from 2007 (Tlusta et al. 2007) also reveals some psychometric properties that can affect the QoL in Czech PWE. The factor analysis states that the most influential factors can be in of emotional well-being and energy/fatigue. The second one is cognitive functioning that can be compromised by the AED. Overall QoL and social functioning can be a more serious issue than seizure worry and medication effects. The cognitive functioning and social functioning together are a stronger factor than driving itself.

On the other hand, a study from 2009 had a slightly distinct output as it included 286 outpatients of two neurology departments between 2005 and 2006 (Tlusta et al. 2009). The most relevant finding for this thesis is the fact, that there is a high percentage of the disability pension among PWE in the Czechia. There are 5 % of the population that receives a disability pension, of which 30 % are PWE. At the same time, this study showed that those PWE with disability pension were having the lowest QoL score in QOLIE-31 (Tlusta et al. 2009). The long-standing interest (for instance, Elliott, Mares 2012; Tlusta et al. 2009) in finding a correlation between gender and epilepsy was not confirmed in studies conducted. Nevertheless, the advanced age as a risk factor was shown only in a total score in QOLIE-31, but was not significant in any of the subscales (Tlusta et al. 2009).

The evidence presented in this section suggests that some distinct characteristics in the Czechia should be acknowledged during the future studies and researches. Moreover, the importance of driving for the Czech population and high percentage of disability pension among PWE highlight the need for the further investigation of the impact factors that can affect to some extent QoL among PWE. Overall, the section presented two validated studies of QoL among PWE in Czechia.

Chapter 5

5. Methodology and data description

Traditionally, the concept of the QoL in epilepsy has been assumed by measuring within the variety of quantitative measuring tools (Micoulaud-Franchì et al. 2017; Kugoh 1998; Celani et al. 2018). As I already mentioned in the chapter 2.5., the measuring tools were aimed to present the most influential areas of the PWE's life and possible correlations with the socio-economic factors (Kováts et al. 2017; Fisher et al. 2015). Nevertheless, the qualitative approach offers an effective way of understanding a sensitive subject and look in details concerning the issue that is not exclusively researched in a particular area, region, or community (Silva, Frag 2012; Sale, Thielke 2018). In the case of this thesis, I would like to point out once more that the topic of the QoL in PWE in the Czechia is understudied. As I have mentioned in the chapter 2.4.1., there was one study concerning the QoL in children with epilepsy that used the qualitative approach. Even though such methodology as any others has its limitation, I would like to present in this chapter the chosen qualitative method of measuring the QoL in Czech women with epilepsy. Moreover, I will describe the data and their collection along with the data anonymization and its limitations.

As it was mentioned earlier, one of the research questions for this thesis focuses on the examination of the primary and secondary influential factors of the QoL among Czech women with epilepsy. It is essential to note that both factors are defined by the subjective importance that was assigned by the respondents in the administered interviews. Therefore, the criteria for the primary factor's characterization were based on the respondent's own opinion. The primary factor itself can be described as "limit", "restriction", or even "dilemma". In addition to that, primary factors were considered as challenging to follow or required a certain amount of adjustment. On the other hand, the secondary factor can be interpreted as "manageable" or even "fine". It did not require any adjustment to everyday life, but still, brought the respondent's attention to a certain extent. Even though the significance of the secondary factor is not as influential as in the case of

the primary factor, it still should be considered and taken into account that it has an influence on the QoL among Czech women with epilepsy.

5.1. Qualitative methods in the quality of life in epilepsy research

Before I start the description of the particular qualitative methods that were used in this thesis, I would like to emphasize that narrative analysis is one of the preferred qualitative approaches in understanding and describing the QoL in PWE (Collard, Marlow 2016; Leahy, Hennessy, Counihan 2018). The narrative analysis can be used in QoL assessment as it is a concept that is rather complex to grasp in the quantitative form (Collard, Marlow 2016). Indeed, the measurement of QoL is a complicated task, and the usual assessment concerns regularly one area of the research and interest (Gutter et al. 2019; Elliott, Mares 2012; Aguirre et al. 2017). There is a definite complexity of even defining the concept of QoL (Felce, Perry 1995) and, in particular, the QoL in epilepsy (McLaughlin 2011). Furthermore, it can be seen by the distinct studies in the field of the social epidemiology that the QoL usually relates to a particular issue (Lim, Chan, Ko 2009), illness (Wolf et al. 2015) or factors (Elliott et al. 2009). In that case, the grasping of the issue can be rather hard for a researcher. Nevertheless, the narrative analysis has the ability to use the language as a tool for the purpose of the detailed description of the issue (Sharp, Bye, Cusick 2019). Therefore, the respondent becomes the main source of the information through the primary contact with an interviewer, who can navigate and transform the questions and the whole interview in a way that will make the respondent rather comfortable to share his/her story and describe a particular issue in details.

The particular advantage of the qualitative methods lies in the primary contact with a respondent or social actor and the possibility to navigate the instrument in order to receive the required information for the research. Furthermore, qualitative research examines the general concepts and their meanings in particular situations and specific conditions (Sale, Thielke 2018). For this thesis, such specifics can be defined as women with epilepsy that are residing in the Czechia. Nevertheless, it was estimated that quantitative measures would usefully enhance and extend the quantitative research, and in some ways prepare the ground for future quantitative studies (Silva, Frag 2012). For this thesis, only the qualitative approach was being used due to practical constraints. Nonetheless, this approach was a fundamental source for the research questions that were stated in this thesis earlier.

5.2. Data and methods

This thesis was exploratory and descriptive in nature. Hence, there was a necessity for data to display the everyday life and struggles of women with epilepsy. Furthermore, there was a necessity to explain the respondents' perspectives towards the illness itself and forms, in which it changes their lives. Consequently, in order to recognize the prominent factors of QoL in the collected sample, the descriptive data should be interpreted in a manner that will maintain the descriptive nature and explore the data thoroughly. That is why the narrative analysis was adopted

for these purposes. The narrative analysis as a qualitative method of the research that was used in this thesis due to the specifics of the required respondents' sample. In other words, the sensitivity of the issue and the descriptive nature of the desired data are the fundamental reasons for choosing this distinct method of analysis.

Indeed, the epilepsy research can be considered as the one that involves several aspects of the person's well-being – social relationships, every day and social life, the nature of the epileptic seizures and the mental state of the PWE. Understanding the prominent potential of epilepsy on these aspects of life among PWE can be a rather complicated task as it is nearly improbable to quantify those aspects in a way that will compose the reality of the PWE. I would like to point out here that those aspects have been successfully quantified in the previous studies of QoL among PWE (Elliott et al. 2009; Lee et al. 2014), although the quantification in the connection to the aims and research questions of this thesis is not the initial task. For this reason, the qualitative methods of analysis and data collection were used, as their descriptive nature is more sufficient for constructing the QoL in women with epilepsy than the average satisfaction with the health condition (Micoulaud-Franchì et al. 2017) or subjective self-assessment of their well-being (Jadhav et al. 2013). Despite the choice of the analysis method, the quantification of the QoL in PWE was used as an illustration during the preparation of the questionnaire, and the further analysis of the collected interviews.

The narrative analysis was used as a tool for identifying the QoL in women with epilepsy and the topics that were presented in those interviews. I would like to kindly note that this type of analysis provides a chance for the comparison between each of the interviews, even though all of the stories are initially unique and distinct in its nature. Notwithstanding, it is crucial to note that such comparison should not be generalized as the qualitative methods do not provide the reliability for the generalization regarding the women with epilepsy in the Czechia and their QoL. Therefore, the collected data and the results should be regarded as a stimulus for additional QoL research in the Czechia and the possible further exploration of the issues regarding the women with epilepsy that will be discussed in this thesis.

Eligible women who matched the selection criteria were identified primarily by the existence of the diagnosed epilepsy that was not caused by brain surgery or trauma to the head[1]. Furthermore, women aged between 18 and 65 were suitable for the interview. The age criterion can be explained by the nature of epilepsy that has its onset in the more adult age. In particular, epilepsy caused by the neurological changes in the brain due to aging may have a distinct effect on the QoL among PWE in comparison with the epileptic seizures' onset in childhood or adolescence (McLaughlin, Pachana, Mcfarland 2008). In addition to that, the questions concerning motherhood and pregnancy are expected to be perceived differently for the elderly women that have the onset of epilepsy later than that determined sample of the respondents.

[1] Epilepsy caused by brain surgery adds additional factors and comorbidities to the underlying issue and may affect the results of the analysis in a way that will threaten the significance of the QoL in women with epilepsy (Téllez-Zenteno, Dhar, Wiebe 2005). Epilepsy that is caused by the head trauma also needs a distinct approach in assessing the QoL as the nature of the head trauma is crucial for understanding the nature of the illness and the triggers of the epileptic seizures (Liu et al. 2011).

The sample of the respondents was recruited by a snowball method (Naderifar, Goli, Ghaljaie 2017) with a help of a Czech Epilepsy Association and the interview with one of the representatives of this organization was conducted in order to obtain a perspective from a third-side member that is dealing with the issues of QoL in PWE daily. This interview was not incorporated in the main part of the narrative analysis for this thesis. However, it provided valuable insights into the everyday travails of the Czech women with epilepsy, which will be described later in the discussion section. Semi-structured interviews were administered with 6 women from different regions of the Czechia, who were at the time of the interview diagnosed with epilepsy. A small sample was accepted because of the expected challenge of obtaining the information due to the ongoing COVID-19 outbreak at the time of the data collection phase. The initial contact information and the consent from the respondents were gathered before quarantine measures were applied in the Czechia. Regrettably, due to epidemiological restrictions that were administered by the Czech government, the original thought of the face-to-face interviews was not achievable. Nevertheless, the face-to-face interviews were replaced by the online video/audio communication with a respondent's consent.

5.2.1. Semi-structured interview

To identify the QoL in women with epilepsy, the semi-structured questionnaire was used during the interview. The questionnaire had the following questions and structure in the English version (for the Czech version please see the Appendix 1):

1. Can you shortly, please, describe you story?
   - Sex
   - A current age
   - Nationality
   - Age of diagnosis
   - The reason of an illness (if known)
   - Type of epilepsy
   - Type of seizures
   - Seizure frequency (number of seizures in the last 12 months)
   - The last time of a seizure
   - Place of treatment
2. Describe, please, your life before being diagnosed with epilepsy.
   - Socioeconomic status
   - A living situation
   - Marital status
   - Level of education
   - Work/School (field)
   - Health issues/medical conditions BEFORE being diagnosed
3. What changed in your everyday routine after you have been diagnosed with epilepsy?
   - Socioeconomic status
   - Employment status (If YES: In which field)
   - Health status (self-evaluation)

- Medications: which kinds, AEDs
- Side effects from medications
- Public spaces – driving

4. Which kinds of activities you are restricted to do because of epilepsy?
   - Employment
   - Sport
   - Leisure time
   - Alcohol/Smoking/Drugs
   - Friends and family (social isolation)
   - Diet
5. Which restriction/limitation is the toughest for you?

How do you deal with them? How do you replace them?

6. What do you think about your quality of life with epilepsy in comparison with others (family, friends)?
   - Overprotection, excessive care, frustration, fear/anxiety, social isolation
7. What would you like to change/add to your treatment plan?
   - Adverse effect of AEDs
   - Number of medications
   - Addition of specialists to a treatment plan
   - Frequency of doctor's appointments
8. How do you see your life without seizures?
   - Health status (self-evaluation)
   - Employment status
   - Education
   - Sport
   - Leisure time
   - Diet
   - Friends and family

The flexibility of the structure in the prepared tool that is typical for this method of data collection has been shown to be an efficient way for both the interviewer and the respondent (Adams 2015). Furthermore, the technique used in this type of questionnaire combines open and closed questions that allow us to comprehensively explore the issue. Therefore, the questionnaire contains 8 open questions, each of which has its subtopics that should be specified either by the interviewer or the interviewee. In case a respondent did not discuss the subtopic during the interview, it was proposed to elaborate on the overlooked issue. Nevertheless, none of the topics were urged to be answered, whenever the respondent was reluctant to discuss the issue. To improve the effectiveness of the data collection process and, in particular, the created questionnaire, it was ensured that the length of the interview would be no longer than 60 minutes.

To enhance the reliability of the questionnaire, it was designed based on the already existing tools for measuring the QoL and the health-related status. The first one is QOLIE-31, which was described thoroughly in the chapter 2.5. This questionnaire was used as an inspiration and a model during the development of the semi-structured interview scenario. Consequently, the questions

about the nature of epilepsy and its effect on the QoL were essential for this thesis as they gave the information that may apply only for this particular sample of the respondents based on the current diagnosis. The second instrument was the California Health Interview Survey (CHIS), which provided an insight into interviewing patients with an ongoing illness regarding their current health status (UCLA Center for Health Policy Research 2013). I would like to point out that both questionnaires contributed to the designed questionnaire in order to take into account the required data for future evaluation. Furthermore, an additional question was put based on the sensitivity of the issue and the likelihood of the constraints to share information by the respondent. The question was proposing to assume a respondent's life without illness. The results of this approach will be discussed later in the thesis, but it is essential to specify that not all questions were based on the earlier mentioned quantitative questionnaires and was either modified or transformed to make a consistent and understandable tool for the respondent that will provide the necessary information for the analysis.

For a greater understanding of the structure of the questionnaire, it can be divided into four sections. The first one contains the first three questions, that have the descriptive nature. The first question in the created semi-structured questionnaire was intended to provide an insight into the onset of epilepsy concerning the respondent. The purpose of this question was to give a respondent time and a chance to introduce herself and to talk about the start of the illness from her point of view. To clarify some aspects of the diagnosis, the follow-up questions about the type of epilepsy and epileptic seizures along with the cause of the illness were asked, if needed. Most of the subthemes were covered by the respondents and required only minor clarifications. The second question was related to life before the epilepsy was diagnosed. Typically, this question was prepared for the comparison of life before and after the once of epilepsy with regards to the respondent's QoL. The next question was concerned with the everyday issues for the women with epilepsy that had changed after the diagnosis. The subthemes of this question were supervised from the QOLIE-31 and consist of respondent's socioeconomic, employment, health status along with the prescribed and taken medications, possible side effects from medication, and the behavior at public spaces. As can be seen in Appendix 1, the subtheme regarding public space has an additional reference to driving. The stress on the driving issue was highlighted in the two QoL in PWE studies that were conducted in the Czech Republic (Tlusta et al. 2007; 2009). That is why it was decided to include this subtopic to the question and clarify it, in case the respondent does not mention it on her own.

The second section of the questionnaire (questions 4 to 6) is focused on the factors determining the QoL among respondents. The fourth question describes the activities that may or may not be altered by the diagnosed epilepsy. In particular, the issue of employment was addressed. The sport and the leisure time were separated in order to divide the limitations that are produced from the nature of epilepsy and side effects from the medications. Furthermore, the subtheme concerning the risk behavior for the epilepsy was attached to this question. The subtheme incorporates the issue of alcohol, smoking, and drugs. It focuses on whenever the respondent is limited in the risky behavior due to the diagnosis and the prescribed medications in comparison with the social network, in which the respondent lives. The subtheme concerning the friends and family was chosen to define the possible ways, in which the respondent was isolated

or dominated by her social network. Moreover, the fifth question was suggested to determine the most demanding limitation for a respondent. In that way, it was partially possible to identify the primary and secondary influential factors of QoL in this sample. In addition to that, the ways of coping or substituting the activities that are restrained were asked. This allowed discovering the coping mechanisms or lifestyle changes that were a consequence of the diagnosis. The closing question in this section was describing the QoL in PWE in comparison with a respondent's social network. In particular, it was concerned with overprotection and excessive care from family and friends. Further, it assumed to elaborate on the issue of the mental state in the context of frustration, anxiety, or fears due to limitations and restrictions. Lastly, it was once again incorporating the issue of the social isolation that is, according to the studies of QoL among PWE. is a pressing problem that leads to low scores on the quantitative QoL scales (Elliott, Lach, Smith 2005; Aydemir et al. 2011; Lim, Chan, Ko 2009). Therefore, this issue needed to be discussed in comparison to others' social relationships among people without a similar diagnosis.

The third part of the interview (question 7) was directed at the present the health aspects of the QoL concerning the doctors, additional specialists, and medications. Since the AEDs plays a crucial role in the QoL according to the studies that were mentioned in this thesis before (Alfaro et al. 2019; Melikyan et al. 2012), the type of the medication, its prescribed amount and the side effects were essential at this part of the interview. The frequency of the doctor's visit (in this case a neurologist) was linked to this question to understand the respondent's demand for the control from the medical specialist. Notwithstanding, I would like to point out that the seventh question that relates to this section was not straight asking about those issues but rather were aimed to find out the obstacles that the respondent may have with the treatment plan. This question was rather focused on the standpoint of women with epilepsy with regards to the current proposed treatment plan and doctor's visit. The subtheme concerning the additional specialist was aimed to find out, whenever epilepsy or AEDs have an impact on the overall health to the extent that the supplementary medical attention is required. Moreover, due to the specifics of the sample in this thesis, it was relating to the issue of the pregnancy in the past or supposedly in the future. This presented essential information about the specifics of the QoL among women with epilepsy.

The last section of the questionnaire (question 8) contains only one question that was supposed to imagine a respondent's life without epilepsy. This question can be understood in two ways and was modified according to the previous statements about epilepsy by the respondent. In case a respondent imagined a life without epileptic seizures or epilepsy at all from the begging, which means that epilepsy had been never diagnosed, the respondent was asked about the possible events that would have been happening in their life. The distinct understanding of this question was used in the situation when the respondent was asked to imagine a life without epilepsy. This means that the respondent was either cured or the epileptic seizures disappeared or were taken under control. In that case, the interviewer was asked about the plans and dreams concerning their life. In several interviews, it was possible to use both options for this question. Such an approach of using the interviewer's imagination illustrated distinctly, how epilepsy changed the respondent's life, and which plans for the future were changed.

In an attempt to make each interviewee feel as comfortable as possible at the time when the COVID-19 outbreak was at its peak in the Czech Republic, the approach of online audio and

video communication was preferred. In that case, safety and empathy during that particular time was the priority. Nevertheless, this approach had some particular distinctions in comparison with the initial thought and the ongoing preparation for the interviews. For this thesis and according to principles of qualitative research an acquisition of informed consent was required, which was prepared beforehand (Appendix 2) and was assumed to be provided to a respondent in a written form for signing before beginning the interview (Shaw 2008). However, in the above-mentioned conditions, the written form was not an option, and the matter was resolved by reading the written informed consent to the interviewee before starting the interview and pausing for an oral consent.

5.2.2. Data management

For the analysis, all 6 interviews with respondents and 1 interview with a representative of the Czech Epilepsy Association were audio recorded based on the oral consent and then transcribed by using a verbatim method (Pope 2000). It is essential to note that the interviews were carried in the Czech language. Nonetheless, the transcription was done in English by using the verbatim method that secured the minimal loss of valuable information. This was done since this thesis is written in English, but the data collection was conducted in the Czech-speaking area. In addition to that, I would like to note that the usage of English is supported by an effort to present a comprehensive exploratory and descriptive analysis for the future examinations in that filed. To guarantee the anonymity of the respondents, the actual names, surnames, and potential identification information that can retract to a particular person were anonymized by simple coding (Nespor 2000). In order to proceed with the analysis, the audio recorded data were put in a written form based on the anonymization codes. The initial identification information about the participants was stored for future references

Data management and analysis were performed using the software "ATLAS.ti Cloud" to implement a comprehensive analysis and observation of the gathered data. I would like to point out that that this qualitative software program was used in the on-line version as at the time of the analysis phase of this thesis, the full version of the program was available only on the computers of the Faculty of Science at the Charles University. In addition to that, the quarantine measures in the Czech Republic made it difficult to use such an option. Nonetheless, the functions of the *ATLAS.ti Cloud* was satisfactory for the narrative analysis. The analysis was verified during the initial phase and then double-checked at the end of the coding for all 7 interviews. After that, the coding book and the codes were reviewed in order to validate the consistency for the further investigation of the analysis results and its discussion.

5.2.3. Limitations

In this investigation, several limitations should be considered. The main limitation is in the sample size. However, the thesis gives an insight into the issue of the QoL in women with epilepsy due to a gap in this area of the research. Nevertheless, the qualitative nature of the data collection and the following analysis provides with sufficient amount of information for the initial aim of the thesis. Another source of uncertainty is in the used tool for mapping the QoL in Czech women with epilepsy. The semi-structured questionnaires are not generally used in the Czech Republic for the QoL assessment and, therefore, the base for the used tool was in the form of the

quantitative questionnaires. Nevertheless, the qualitative methodology was utilized in other studies to examine related issues regarding epilepsy (Leahy, Hennessy, Counihan 2018; Townshend et al. 2008). Moreover, it is essential to consider once more, that there were changes in the data collection and data analysis due to the COVID-19 outbreak, which were resolved by using a different approach to the method of data acquisition.

Chapter 6

6. Findings

To assess the QoL in Czech women with epilepsy, the semi-structured questionnaire was used to conduct the interviews with each of the respondents individually. After that, the narrative analysis was applied in order to code 7 interviews that were collected by audio/video communication. In this section of the thesis, I would like to elaborate on the findings that were observed during the narrative analysis. The principal aim of this section is to present the interviews, the discovered themes in each of the interviews, and their main features in the context of the used questionnaire.

The six respondents recruited for the semi-structured interview were diagnosed with epilepsy at the different ages varying from 1,5 to 19 years old. Furthermore, the socio-economic background and the current age of the women with epilepsy were distinctive. Five of the respondents are currently working, one is on the maternal leave. Four of the women are also studying at the university. Three respondents have an unknown reason for epilepsy, two have located benign tumours in their brains, and one of the respondents has epilepsy that is triggered by the hormones. Five of the women are currently taking different medications, one is off the AEDs. Regarding the driving license, only one interviewee is currently holding one. From the five of the women without the driving license, one had it previously, but was denied after the diagnosis. Two of the interview women have children.

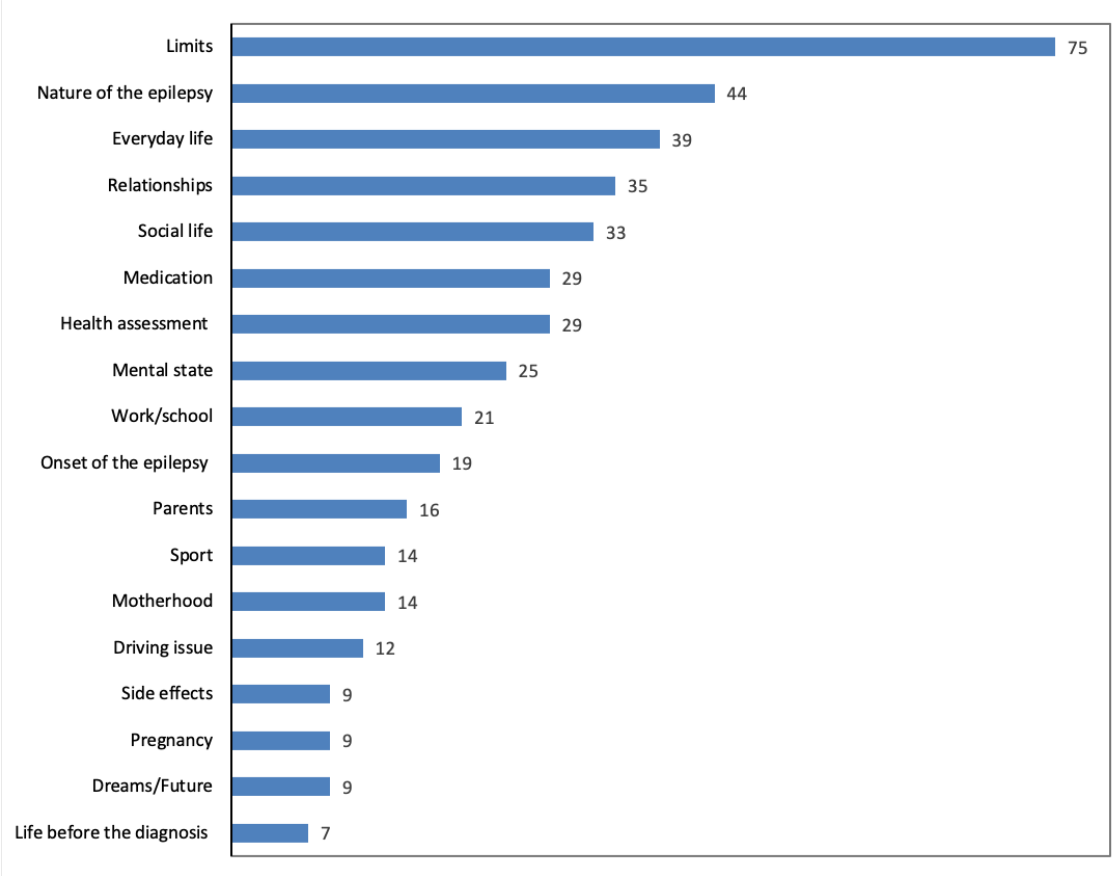
6.1. Coding book

Based on the collected 6 interviews with the women, who have diagnosed epilepsy, and the administered narrative analysis, there were distinguished 18 theme codes. Figure 6 presents an overview of the established codes during the interview. It is vital to note that the frequency of the codes links to the quotations that were identified with the theme codes. Therefore, the frequency in Figure 6 is not displayed as a statistical variable that describes the codes' frequency, but rather

theme mentions during the conversation. Furthermore, the quotations were usually coded with several codes.

It can be seen from Figure 6 that the QoL in Czech women with epilepsy was divided into certain themes, where the limitations are the most discussed ones. Nevertheless, the side effects of AEDs and the topic about medication are also are part of the nature of epilepsy and its limitation, but it was distributed into distinct codes due to the nature of the explanation and the respondents' attitude towards these issues. The themes identified in these responses were established almost in each of the interviews, except for one, where the respondent was reluctant to address the issue of motherhood and pregnancy. Therefore, these two themes were not part of this interview.

Figure 6 – Health-related QoL for PWE – frequency of the mentioned themes during interviews



Resource: interviews, ATLAS.ti Cloud

From this data, we can recognize that theme concerning the limits was assigned a separate code. This was done to highlight this theme in the analysis for further investigation, which will be discussed in the discussion section. Interestingly, during the data collection and the analysis, it was explicit that the respondents were dividing the impact of epilepsy on their social life and everyday life. Those two themes were initially put in one code. However, it was apparent during the analysis that they should be separated. Following the addition of the *Dreams/Future* code to the codebook, additional mentioning of the limits and side effects were provided. Therefore, the original thought of profiting from the last question in the questionnaire "How do you see your life without seizures?" was proved to be convenient for the elaboration from the respondents concerning the issues that were omitted or consciously hidden during the interview.

6.2. Semi-structured interviews

The first question was the most elaborative for the respondents as it was originally assumed to be. In addition to that, the question further granted insight into other questions and additional information about attitudes towards the onset of the illness. It was not merely the description of their first epileptic seizure or the story from their parents, in case their onset was in the early childhood, it was also an chance to understand their perspective and emotions at that time and from the current viewpoint. In response to this question, most of the respondents covered the subthemes by themselves. Rarely, there was a necessity to clarify the type of epileptic seizures or the last time of a seizure.

Interestingly, the second question, that was designed to identify experiences before the diagnosis, was used as a separate question just in one interview. For the other 5 interviews, this particular question was not used as a separate one, rather the subthemes were clarified as the principal information that was supposed to be collected from this question was previously answered during the first question. In other words, the description of life before epilepsy was diagnosed was answered in the narrative of the illness's onset. When the respondents were asked about their health before the diagnosis, all of the women stated that there were no health issues, and the first epileptic seizure was not prognosticated by any other ongoing medical condition. However, some of the respondents declared that before the initial epileptic seizure, they were under a considerable amount of stress.

The third question in the questionnaire was focused on the changes that the diagnosis of epilepsy caused to their lives. None of the respondents indicated that there were any alterations in the socioeconomic status. Instead, it was regularly declared that their plans for the future were adjusted or no longer made sense and required additional reflection. Those plans were frequently concerning future employment and the choice of future education or major. 5 of 6 respondents had changed the initial plans for the future concerning school. A common view among interviewees was that there is a big dilemma regarding the driving license in Czechia. Moreover, this issue corresponds with the interview that was conducted with the representative of the association that helps people with epilepsy, as the questions around the driving license are one of the most frequent ones that are received at this organization.

The limitation topic came up not just during the question that was focused fully on the restrictions in the everyday life but also on the question that was focusing on the changes in the respondents' lives and the last question of the questionnaire. Several limitations were identified during the description of life without epilepsy. Some women claimed that they would probably have a distinct career path, while others were convinced that the epilepsy is something that should have happened to them no matter what. A variety of perspectives were introduced on the issue of the society's perception of epilepsy and the required changes in that area to make PWE less restricted. As one of the limitations, the respondents mentioned a fear of the majority of people dealing with an actual epileptic seizure. This limitation, which was not entirely because of the nature of the illness, but to some extent a societal reaction to the illness, was considered to have an impact on their other limitations and choices according to respondents.

The section of the interview that was focused on the health issue revealed that mood changes, anxiety, loss of memory, and lack of concentration are present among PWE. Nevertheless, it was not possible to find out, if these symptoms are because of epilepsy or the AEDs. Nevertheless, all respondents reported that they are satisfied with the current health despite the side effects and the medication. Furthermore, the health issue was also present in the section of the limitations. In particular, some restrictions and limitations were a result of the high likelihood of epileptic seizures. Some of the activities or places were recognized to be a trigger for the seizures and, as a consequence, were avoided or limited. What was more engaging in this section is that despite some concerns for their health, the respondents were rebelling against them to some extent.

If we now turn to the question regarding life without epilepsy, the earlier mentioned two-way of understanding this question provided valuable information for the analysis. In particular, the initial plans and the required changes after being diagnosed with epilepsy were revealed, even though some of the respondents were reporting that there were no modifications or changes because of it. Talking about these issues, every respondent reacted surprised to some extent by this question. The reactions to this can be divided into two categories. The first one acknowledged the imaginative part of the question: "Wow, this question is for some imagination". The other reaction was the recognition of never thinking about life without epilepsy: "I have never thought about it like this". Taken together, this section of the questionnaire was engaging for both the respondents and me as an interviewer, mostly, during the analysis.

Comparing the answers to the theme sections of the questionnaire, I would like to emphasize another issue apart from the respondents' attitudes towards epilepsy itself and the societal perception of the illness. Here I would like to point out that the motherhood and pregnancy themes, which were mentioned in the section regarding the coding book, were brought up during the entire interview almost in every section, except the one that was focused on the onset of the illness. Even though there were no specific questions and subthemes regarding these issues, the motherhood and/or pregnancy was brought up in the 5 of 6 interviews. This was mentioned mostly during the discussion of limits and restrictions. For instance, one of the respondents perceived the pregnancy as a restriction since it was advised by doctors to avoid having children due to the nature of epilepsy. Overall, this proves the initial thought that there are specifics of the QoL in women with epilepsy.

The result in this chapter indicates that the QoL in women with epilepsy is a multidimensional issue that includes not solely the changes to the everyday life and the struggles with the side effects of the AEDs but also the societal attituded towards epilepsy along with the health-related issued regarding the pregnancy and the motherhood. The next chapter, therefore, moves on to discuss the results in detail regarding the previously discussed QoL in PWE studies among the discovered issues in the above-mentioned interviews.

Chapter 7

7. Discussion

As it was stated in the literature review and the theoretical section of this thesis, the QoL in PWE can be divided into several factors. The distinction of the affecting factors of the QoL that was presented earlier explained the issue of the gender, clinical, and psychological factors. Nevertheless, it is crucial to recognize that one of the aims of this thesis is to distinguish the influential factors into two categories – primary and secondary factors. The first part of this Chapter will be concentrated on this particular distinction. The second research question in this thesis was proposed to determine to what extent epilepsy can alter the person's QoL based on respondents' subjective assessments and personal experiences. Moreover, the subjective assessment has been accepted in the interview with the representative of the specialized organization that offers help for PWE.

It was hypothesized that the QoL in PWE is not distinct among males and females (Yue et al. 2011; Elliott, Mares 2012). Nonetheless, the comprehensive understanding of the issue revealed an unexpected finding. In particular, the issues of motherhood and pregnancy were brought up by the respondents themselves without the specific question or subtopic of this kind in the semi-structured questionnaire. Consequently, those two factors were included in the qualitative construction of the QoL in women with epilepsy. Before I start to determine primary and secondary factors of the QoL in this sample, I would like to point out that these presented findings cannot be generalized to the wider population or the Czech population. That is why it is essential to recognize that the proposed construction of the QoL in this sample is based on the previously discussed literature, the collected data both from the respondents' and the representative of the organization for PWE. Nevertheless, the significance of the findings should be still seen as valuable for future investigations.

7.1. Primary factors

For establishing the primary factors of the QoL in women with epilepsy, the notion of the importance based on the narrative analysis combined with the literature review was taken into account. In the current thesis, the primary factors can be affected by a variety of different conditions including the fact that the interviews were conducted during the COVID-19 outbreak. In addition to that, the additional stress along with the feeling of the uncertainty could add weight to the respondents' mental states (Torales et al. 2020; Horesh, Brown 2020). Nevertheless, primary factors can be perceived mostly as the ones that are dependent on the social world and social attitudes towards epilepsy.

7.1.1. Social life

The social life of the respondents provided with one of the most prominent sources of the information regarding the limitations associated with epilepsy, societal attitudes towards the illness, and the respondent's perception of the social opinion on the same matter. Nevertheless, there is a common sense of rebellion against some of the restrictions. In addition to that, the sense of not full enough engaging in life may have additional stress to a person and, therefore, this can have a significant effect on the QoL. One of the respondents that have epilepsy for 10 years explained the rebellion against all recommendations in this way:

> *"I think that I was losing time as I was not attending anything in my teen years and I just decided it is enough. I will not wait for life and being afraid of having a seizure. It was about a time and it is passing. I was older and older and have not experienced a lot, so I decided to do everything. I want to do everything and change. I want to graduate from school, have a tattoo, write a book. I am gradually doing this. I am working on the book now. I applied for school. I started planning."*
>
> - Š, epilepsy onset at 18 y.o.

The notion of missing something in the social life was a common theme between respondents, and these results agree with the findings of the other QoL in PWE studies that state that the social isolation deriving from the nature of the illness later can be a reason of the worsening mental state and the down spirit (Elliott, Lach, Smith 2005; Collard, Marlow 2016). For instance, the feeling of being "different" can lead not to increased social support that lacks among PWE, but to the feeling of being an outsider. As one interviewee said:

> *„So, in the beginning, everyone was getting used to it, and then they were accepting this as normal, but I was a lot as an outsider. "*
>
> - L, epilepsy onset at 3 y.o.

The social isolation in that context is a source of the misunderstanding or the lack of information regarding epilepsy. One of the mentioned struggles with the social acceptance from

a social network, in which the respondents were at the time of epilepsy's onset, was mentioned in the following way:

"It was uncomfortable for me - the social life was hard as I needed to admit to someone that I have epilepsy, and everyone was asking about what it is, and how can I understand that this is it [a life with epilepsy]. A lot of people just googled it."

- Š, epilepsy onset at 18 y.o.

Furthermore, the acceptance from peers was considered to be an issue and, at the same time, a source of social isolation to some extent as several respondents discussed being excluded from "normal life" due to restrictions and the necessity to follow a daily routine. As the same interviewee put it:

"One of friends was ready to go to my home and get my pills so that I could stay longer [at the party]."

- Š, epilepsy onset at 18 y.o.

These findings support the previous research on the effect of the social isolation on the QoL in PWE and, therefore, it can be stated that a similar situation was witnessed (Collard, Marlow 2016; Charyton et al. 2009). Nonetheless, I would like to turn now to the topic of social isolation that is partly deriving from the overcarrying and excessive care from the respondents' parents. Because of the specifics of the sample in this thesis, the parents' theme was discussed by every of the interviewed women. In addition to that, the significance of the mother-daughter relationship was evident in some of the interviews, which corroborates the ideas of Lougheed, Koval, Hollenstein (2016), who suggested that there is a partial sharing of the stress between the mother and the daughter. This relates essentially to the situations, in which a daughter is in the distress. Regarding this issue and taking in mind that all participants were women, it was possible to look into the relationship in a more detailed way. For instance, the one interviewee said:

„After the status epilepticus, even at 17, I wanted to go out with my friend, but my mom immediately prohibited it that I cannot go there in case something would happen. She always thinks about the worst-case scenario."

- A, epilepsy onset at 9 y.o.

The issue of the control concerning a teenager with epilepsy was also a point that, according to the respondents, was a part of epilepsy that prevented a respondent from having a social life to the full extent. The comment below reveals that such control was not perceived as a powerful limitation, but rather a way of adjusting to the life with epilepsy, which was frequently considered as an issue for the PWE (Ring et al. 2016; Leahy, Hennessy, Counihan 2018; McLaughlin 2011). For instance:

"Parents were cautious with me, and whenever I was doing something that I was supposed not to do, they prohibited me then. As I was small, I did not care for it. The behaved normally."

- A, epilepsy onset at 9 y.o.

The next part of the social isolation in PWE that affects the QoL in Czech women can be described as the limitations and restrictions that are representing the leisure time. It should be mentioned that sport was considered as a secondary factor and was not even perceived as leisure time, but rather as a part of a lifestyle. As for leisure time, the respondents tended to refer to music concerts, festivals, and discos. Nevertheless, for those, whose epileptic seizures are triggered by the blinking or strobe lights, there are some precautions. Nonetheless, identifying the triggers and their consequences were partially considered as a restriction to fulfil the leisure time and enjoy it to the full extent. There was a common sense of frustration in several respondents regarding this issue. The present finding seems to be consistent with other research, which found that PWE with meticulous control of their triggers for the epileptic seizure provides the ability to fulfil the leisure time independently (Unsworth 1999). Talking about this issue an interviewee said:

„I am visiting the concerts, but I will take sunglasses, but I just like music. Other people are looking at me, but I am just living with this, and they can think whatever they want, but I want to enjoy a concert. "

- D, epilepsy onset at 19 y.o.

In the final part of social life as a primary factor affecting the QoL in women with epilepsy, I would like to discuss the issue of the addictive substances. Earlier observation seems to be consistent with the respondent limitation in this area regarding such substances as alcohol, cannabis, and nicotine cigarettes, which can trigger an epileptic seizure (Leahy, Hennessy, Counihan 2018; Johnson et al. 2019). Nonetheless, there seems to be a misconception about cannabis use. Even though according to the previous research, cannabis is usually used as a kind of treatment for PWE (Holtkamp, Hamerle 2015), several respondents perceived it as a risk factor that can trigger an epileptic seizure due to its effect on the brain. On the other side, the restriction about alcohol was followed by the respondents differently, including being fully abstinent and being able to have "a glass or two". One interviewee described the issue of being restricted to alcohol and its effect on her social life in the following way:

"Then, on the New Year Eve people were gathering money for the booze only, and I wanted very much to attend this celebration, but so that they would not get mad that I will have only one glass and no more. So, it was logical not to give the same amount of money to them as I will have only one glass. Instead, they wrote me that it is naive to think that. I collapsed because of it as I wanted to spend this time with my friends, and I was not thinking of getting drunk, but they were thinking about booze."

- H, epilepsy onset at 14 y.o.

These findings describe to what extent the social life of the respondents has been affected by epilepsy. The perception of being isolated and bullied by the peers are mostly derived from the inability to stay late at a social event as there is a consequence of not following sleep hygiene and daily activities regime for PWE according to Leahy, Hennessy, Counihan (2018) and Räty, Söderfeldt, Wilde Larsson (2007). In addition to that, there is a particular problem with alcohol consumption that affects social life in a way that is essentially preventing to attend social events. The issue of alcohol consumption can be considered as a part of the culture and general social life in the Czechia that according to Popova et al. (2007) has one of the highest rates of alcohol consumption in Eastern Europe. Overall, the nature of epilepsy and epileptic seizures can have a substantial effect on the QoL in women with epilepsy due to various limitations and restrictions that are part of their everyday life. The issue here lies in the particular extent of the effect on social life, which results often in social isolation and the lack of understanding and/or acceptance from peers and friends.

7.1.2. Lifestyle adjustments

Lifestyle adjustments, as a part of the primary factors, can be considered in the context of the comparison with people without epilepsy and restriction it may have on the daily activities. In this section, I would like to introduce the issue of employment and school along with the daily regime, everyday relationships, and, most importantly, the driving license issue since it appears to be a considerable limitation of the freedom among Czech PWE (Tlusta et al. 2007). Furthermore, the issue of the employment is not new for QoL in PWE assessment (Yagi 1998; Tlusta et al. 2009). Nevertheless, it is rarely discussed that in PWE with childhood or adolescence onset of the illness can have challenges regarding their future career path and the choice regarding education in general. As these areas of every day required particular adjustments to some extent, these subthemes were gathered into one primary factor.

The theme of everyday challenges at work is stemming from the nature of epilepsy, triggers for epileptic seizures, or side effects from the medication. These factors can influence work performance, quality, or required time for some assignments to be done. This corresponds with Jacoby (2002) that claimed that the nature of epilepsy and the lack of the publicly accessed information regarding this illness can lead to the stigma and feelings of the shame and guilt for being not able to do particular activities due to the illness. As one interviewee puts the issue of the lack of information regarding epilepsy and the public perception on the PWE's everyday life:

"People are not expecting to have a university degree for a person with epilepsy. I do not why it is like that, but those myths are there. Society just does not have enough information."

- S, epilepsy onset at 1,5 y.o.

The expressed surprise from people of hearing that PWE can manage and adjust their life to make it possible to graduate from a university leads to a thought that it may be not just the nature of the illness and the PWE by him/herself, which are limiting daily activities and affecting the QoL among PWE. Instead such logic ends in a belief that it is a public opinion that contributes to the QoL to a much greater extent. This corresponds with the work by Lua, Neni (2011). This is

not the only mentioning of the societal attitudes that influenced or even limited QoL among women with epilepsy during the interviews. The same interviewee described her concerns within the society and its perception regarding epilepsy with the expression of genuine fear and concerns for her well-being:

"People do not know how to provide first help for people with epilepsy. It is tragic, I am afraid that people will rob me or something like that. People do not know what to do, they put things in the mouth. I am afraid of that. I just live in the fear of that."

- S, epilepsy onset at 1,5 y.o.

The societal perception and even stigma to some extent regarding PWE were described by Jacoby (2002) using Goffman's understanding of the illness in general and the stigma around it. Nonetheless, the distinct approach to the particular extent towards such areas of life like work can be considered as a valuable illustration of the QoL in women with epilepsy. Some authors have speculated that due to the unpredictable nature of the epileptic seizures, the restrictions regarding the employment and driving should be taken into account (Lua, Neni 2011; Yagi 1998; Martinović et al. 2010). For instance, one of the women described the problems with employment in the following way:

"I work with my husband. I admit and know along with my husband that I can relax at work. I know that at the classic workspace I will not handle it, because I can be sometimes tired and it is a big problem…If I hadn't my husband as a boss at work, I admit that I would have changed my job. Not every boss would tolerate this."

- D, epilepsy onset at 19 y.o.

In addition to that, it appears that the obstacles with employment begin even at the entry interview with a potential employer. Several of the respondents were fine with telling about their condition at the interview, while others admitted it to be a possible risk that can result in not being offered this position. I would like to emphasize here that selected women worked in diverse areas and, therefore, they do not share the same working space or field. Nevertheless, there are two groups of opinions regarding the start of employment. One of them can be described through the words of one of the interviewees:

"I just did not tell that I have actually epilepsy during the interview. I think that it is a big risk for the employer. They would rather have a healthy person."

- S, epilepsy onset at 1,5 y.o.

On the other hand, there is a notion of embracing the issue and „doing this for my safety", as one of the respondents talked about telling family and friends about her condition. In summary, the same approach was taken by several of the interviewed women concerning job interviewees. It was perceived as being sure that people know what to do in case of an epileptic seizure. One of the women, when asked about the restrictions at the workplace, said:

"I think that epilepsy should be mentioned in the CV and mentioned during the interview. I understand that it is a risk, but now people will just deny and do not even ask when the last seizure was and why. I will rather continue to have it in my CV so that the employer can ask about it and discuss it. 100 percent will mention this."

- H, epilepsy onset at 14 y.o.

To conclude this section of the everyday adjustments as a primary factor that impacts the QoL of women with epilepsy, I would like to note that all of the respondents were over 18 years old, and the theme regarding the issues of work was anticipated based on the prior QoL among PWE studies that were highlighting the stigma and stereotypes about epilepsy that is transforming PWE's life, especially at workplaces. Furthermore, the frustration of having a special everyday routine is crucial for seizure prevention from a clinical perspective (Leahy, Hennessy, Counihan 2018). Nevertheless, it appears that such precautions for PWE are changing their QoL and ending in social isolation, misunderstanding, and stigma. It is vital to note that other primary factors may influence the QoL in women with epilepsy.

7.1.3. Driving license

If we now turn to the driving license issue and driving among PWE, which was earlier discussed in this thesis, it may seem that this topic can be viewed rather as a secondary factor. Nevertheless, as I have already mentioned in this thesis that one of the specifics of the QoL among Czech PWE is, according to Tlusta et al. (2007), the denial or inability to have a driving license as a restriction of freedom and free will. However, this result has not previously been described in other QoL in epilepsy studies (Unsworth 1999; Piazzini et al. 2008). Therefore, this should be regarded as a characteristic feature of the QoL in the Czech Republic. Based on this information, I was engaged in addressing this topic with selected respondents. Indeed, the issue of driving was perceived by the majority as "a big dilemma" or "being afraid" of arranging one. It should be noted that a driving license can be denied or taken from PWE based on the diagnoses. This is done according to the Czech law (Zákony online). Nevertheless, only one of the respondents has a driving license, and this was previously discussed with the doctors. She described this particular situation in the following way:

"I was able to do it 2 years later, because the neurologist said "No, in no way, you have there the limit points at the graph. You need to wait". So, I was later under observation, for a week I was in the hospital and they were gathering all information. Finally, they allowed, and I am driving now and everything."

- L, epilepsy onset at 3 y.o.

On the other hand, one of the women had the driving license before being diagnosed as the onset of epilepsy was at 19 years. Nevertheless, she is prepared to obtain it back as soon as it will be possible considering her AEDs and seizure control. For the rest of the respondents, the driving license is considered to be a limitation that may be resolved in the future. However, several of the

interviewees expressed the fear of sitting behind the wheel. The comment below shows the overall worries of driving due to the risk of having an epileptic seizure and harming people around:

"I do not have a driving license, but I was thinking about it for a long time. It is a big dilemma for me. According to the doctor, I can have it, but I am afraid. I am scared that I will get a seizure as I will not be reactive for a while. If I get a seizure while I will be driving, I will be out for a while. I do not know. It is more because of others than me."

- S, epilepsy onset at 1,5 y.o.

In addition to that, the same respondent mentioned that the absence of the driving license is a substantial limit regarding the job offers' requirements:

"I think that the driving license is the biggest limit. I want to change my job, but everywhere is needed the driving license. I may need to have it because of the work."

- S, epilepsy onset at 1,5 y.o.

Taken together, the driving license is modifying the QoL in epilepsy due to fear of harming the others, the general fear of taking the seizure under control and being without the medication for a remarkable amount of time. Here I would like to note that such requirements from the doctors to the patient may result in additional stress for PWE and, therefore, worsen the well-being in general (Charyton et al. 2009). Nevertheless, driving is a pressing issue from the perspective of public safety. Moreover, a driving license may be denied not only for PWE but also for people with diagnosed dementia (Fraade-Blanar et al. 2018) or obstructive sleep apnoea (Morsy et al. 2019). Therefore, epilepsy is restricting this part of the life for PWE, which was established during the interviews along with the complex procedure of obtaining one. The results in this section confirm the previous QoL research in the Czechia and the significance of the driving license for the Czech PWE.

7.1.4. Medications

The topic of medication includes not only the need for developing the routine of taking them in a particular time and day but also their side effects. Regarding the side effects, it should be noted that they are affecting the QoL in PWE to a substantial degree. During the interviews, it was apparent that the issue of taking the medications was restricting only soon after being diagnosed, and it was a part of life adjustments. On the other hand, the side effect of the long-term use of AEDs was considered to have a severe impact on the interviewed women. Taking about this issue an interviewee said:

"These 2-3 years we are trying to find a proper medication. One of the drugs we canceled on my demand, as they muted me a lot and it was not working for me."

- D, epilepsy onset at 19 y.o.

The selection of the proper medication was a pressing issue with the doctors for the recruited women. This was mostly due to the addictive nature of the medications or side effects. One of the interviewees felt that anxiety was a side effect of her AED and after the consultation with a doctor, one particular AED was cancelled, which helped her mental state after all. It should be noted that this particular respondent was having anxiety in the past and was referred to a psychologist, which helped to control anxiety and manage stress. Following the present results, previous studies have demonstrated that AEDs can have as side effects several mental health conditions including anxiety, depression, and suicidal thoughts (Jadhav et al. 2013; Fisher et al. 2015). One respondent described the common side effects of AEDs as following:

"Now I feel that I am fine, but I think that I do not need Rivotril as it is not for my condition. Moreover, it has a physical and physiological addiction and it is hard to overcome it. I think that this is the big side effect. If the level of this medication becomes lower, my condition is bad anxiety and worsen focus. "

- S, epilepsy onset at 1,5 y.o.

Furthermore, I would like to note to the factor of medication that one of the respondents expressed her concerns for removing the medications as it gets the seizure under control. Despite the side effects and the necessity to follow a routine for taking them, the role of AEDs that is aimed at the seizure control is far more valuable for the QoL among PWE. As one interviewee put it in the following way:

"Then, I forgot to take my medication and had a seizure. Now it is 5 years without seizures. I am taking medications. In the last 6 months, I was offered to discontinue them, but now due to stress during the exams and bachelor thesis, I do not think that it is not a good idea. I said that maybe after that."

- H, epilepsy onset at 14 y.o.

Interestingly, one of the interviewees explained her situation with the AEDs in the context of the lockdown during the COVID-19 outbreak. This corresponds with the current studies describing the situation of patients with different conditions that were suffering because of the lockdown and restrictions that made them either isolated in their own homes or with limited access to the doctors or medications (Brigo et al. 2020; French et al. 2020). The extract below shows the issue with accessing AEDs during the lockdown in the Czechia:

"Zonegran is now hard to find because of the problems with the distribution in those conditions [coronavirus lockdown]. I have tried a lot of medications, and they were having a variety of side effects. I asked to send me a prescription for more packages of the Zonegran due to the current situation. If I do not take it, it is a big deal - it has a physical and psychological addiction."

- S, epilepsy onset at 1,5 y.o.

In summary, these results show how the medications, AEDs in particular, are an essential part of the seizure control for PWE. As the seizure control has been established to be one of the key factors for the QoL, it is crucial to note that it contributes not only to seizure control but additionally side effects from a long-term perspective (Ring et al. 2016; Alfaro et al. 2019). To be exact, the side effects of AEDs are limiting and reducing to some extent the QoL both in the context of school, work, driving, and motherhood for the respondents.

7.1.5. Pregnancy and motherhood

The issue of the pregnancy in female PWE and its effect on the QoL has been previously discussed in several studies (Santos et al. 2018; Bala et al. 2016). This topic refers also to the AEDs that are required for epilepsy but can potentially affect the pregnancy (Tabrizi et al. 2019; Santos et al. 2018). As one of the interviewees said:

"We agreed that we would discontinue medication gradually because I was planning my pregnancy. We agreed that the year before we will start to do it, but she said to see in 6 months. So, the discontinuation will be very slow."

- S, epilepsy onset at 1,5 y.o.

Even though the initial plan was modified in the process because the doctor did not follow through with the AEDs' discontinuation, and it was done by the respondent. The medication needed to be cancelled, which influences the QoL in a way that the pregnancy needs to be planned at least 6 months. In addition to that, the medical attention to the female PWE during the pregnancy is something that should be taken into account as the check-ups should be not only with the regular specialist's like a gynaecologist, but also a neurologist to supervise not only the pregnancy itself, but epilepsy and, mostly, epileptic seizures. Regarding this issue, the respondent, who is currently a mother of two healthy children, described her first pregnancy like this:

"The first one was a little bit complicated, but not because of epilepsy. When I had the first child, I was under the doctor's control a lot. My doctor asked me to visit her at the moment of the pregnancy. It was seven years after the last seizure, and my doctor was still checking me with, like, EEG, but she saw that I was fine, and the pregnancy is good. She checked me out of her register. After that, I had the early childbirth due to different problems. I think it was linked with epilepsy somehow, but nobody knows it for sure."

- D, epilepsy onset at 19 y.o.

On the other hand, epilepsy can be also a restriction for future pregnancy, which leads to a direct effect on the QoL. One respondent received a recommendation of not planning the pregnancy due to the nature of her epileptic seizures, which are triggered by the hormone changes. She describes her situation in the following way:

"I am afraid of what will happen in the future during pregnancy due to hormones. I want family, but I am afraid that this will make problems. My doctor told me that I should not have

children, which made me cry. I love children and cannot imagine my life without them, and people with epilepsy around me have children. So, I am thinking about it, but I am afraid of those hormones, and them going crazy. I will be a big risk, my gynaecologist said it too. I will need to be more cautious."

- H, epilepsy onset at 14 y.o.

The pregnancy and motherhood for the women with epilepsy can be considered to be a stressful time in the beginning, as it has its challenges due to the hormonal changes and the stress. Furthermore, one of the stress sources is a fear of having an epileptic seizure in front of the child or while doing any activities with them. One of the women illustrated her epileptic seizure, while she was holding a new-born like this:

"The baby was in the crib, and I was looking at him, and I was thinking of taking him to my arms, but then I decided not to. I am just taking a risk with him that I will have a seizure. It is very hard. It was a breaking point."

- S, epilepsy onset at 1,5 y.o.

In addition to that, the motherhood in the context of raising children has a perception of being afraid that epilepsy can be a genetic condition. Even though there is no accurate evidence of the genetic nature of epilepsy, but at the same time, several studies are rejecting this hypothesis (Moráň 2007). This insight was illustrated in the following way:

"There is no risk of the genetic nature for my children, but as I was afraid as my first daughter was early, she had some neurological problems. We needed to make sure that it is not something like that, but she is fine. Then, my son is growing fast for his age, and he is a big thinker, and it seemed like he was gaping, but this happens from a little age. When he went to school, it was a problem, because he was just gazing and was not reactive for a while. So, we needed again to make sure that it is not epilepsy. He is also fine."

- D, epilepsy onset at 19 y.o.

Together these results provide important insights into influences on the QoL that are deriving from pregnancy and motherhood, an actual one or hypothetical. The impact is not only on the mental state as a stress trigger for the epileptic seizure, but also a physical one such as hormones changes, the adjustment to the daily routine and activities. Moreover, there are a responsibility and fear of having a seizure in front of the children that can limit their everyday or social life as one of the women mentioned during the interview.

7.2. Secondary factors

The secondary factors are the ones that were mentioned by the respondents but were not considered by them as having a significant impact on the QoL. In addition to that, these factors were not mentioned by each of the respondents or even perceived as a factor that influences their

QoL. Therefore, these factors should be considered in the construction of the QoL in female PWE but to a limited extent. This section of the thesis will describe the effect of such topics as the mental state of the PWE, sport, and comorbidities.

7.2.1. Mental state

The importance of the mental state among PWE has been already widely discussed by Yeni et al. (2018), and also in this chapter in connection with AEDs and various side effects. Nevertheless, it has been reported that PWE are suffering from anxiety and depression disorder (Hoyos et al. 2017; Petersen et al. 2004). These findings were confirmed during the interviewees. One respondent described her anxiety that is linked to epilepsy like this:

"I visited psychologist as I was having anxiety and fear of waking up, and all this was bothering me, and I wanted to get rid of out and the psychologist was recommended. The fear of waking up and the night anxiety just disappeared. Then, I think that the use of the Keppra helped, too. The anxiety attacks completely disappeared."

- H, epilepsy onset at 14 y.o.

The anxiety itself as a mental disorder has its significance regarding the QoL as it was discussed by (Mendlowicz, Stein 2000). In addition to that, the anxiety as a result of epilepsy adds an impact on the QoL. Furthermore, one of the interviewees recognizes the importance of her mental state as a trigger for an epileptic seizure. On the other hand, she agrees that there is a desire to deal and acknowledge the illness as less as possible, but there is an intention to look after her mental state more as it can prevent epileptic seizures and their frequency. She commented on this issue in the following way:

"In my own experience, mental health is playing a big role in it, because for me the biggest trigger is always stress."

- D, epilepsy onset at 19 y.o.

Comparing the above-mentioned comments, it may be recognized that interviewed women with epilepsy are acknowledging and accepting their illness as it is. However, other women were not that confident and tolerant of the illness itself. Talking about this issue, one respondent said:

„I am not entirely fine with the fact that I have it."

- S, epilepsy onset at 1,5 y.o.

The feeling of being „normal" was mentioned in several interviewees and it was considered to be a goal for the women. This result corresponds with the findings of the study (2018). The notion of the „Cinderella syndrome" comes to a mind, where it is crucial to maintain a semi-normal life, which affects the QoL not in a direct way, but rather through the restrictions that are required to maintain a plausible health condition. One of the respondents put it like this:

"I think that I accepted it. I was afraid of everything, but now I try to feel normal."
- Š, epilepsy onset at 18 y.o.

Overall, these results indicate that the mental state for PWE is significant to maintain sufficient QoL, but at the same time, it can be perceived as a tool for seizure control. In addition to that, the disturbances in the mental state of women with epilepsy may derive from the medication and, therefore, the additional social and medical support is needed. Even though only one of the respondents were visiting the mental health specialist for the anxiety, it is highly recommended by the various studies that are aimed to find ways of increasing the QoL among PWE (Chen et al. 2016; Barahmand, Haji 2014). However, self-help was mentioned in the interviews, which was for the majority described as regular physical exercise in the daily routine among PWE (Collard, Marlow 2016).

7.2.2. Sport

In this section of the thesis, I would like to describe how sport affects the QoL among PWE in several areas, but before that, it should be noted that studies focused on the significance of the sport for PWE suggests two ways in which it may have an impact, which will be discussed later (Tedrus, Sterca, Pereira 2017; Aguirre et al. 2017). Furthermore, this issue was the one that was perceived by the interviewees with skepticism and was occasionally rebelled upon. Despite the recommendations and the risk of the condition worsening, several respondents were not accepting such limitations and were doing prohibited sports activities anyway. One of the examples of such rebellion despite the doctors' recommendation was described like this:

"I was doing sports, even though I was not supposed to do some things, because the neurologist prohibited any kind of sports that can affect the brain - hits to the head or physical pressure. So, I was doing martial arts for 16 years, where I was falling on the floor and walls. Several times I received kicks to the head."
- L, epilepsy onset at 3 y.o.

On the other hand, sport proves to be a cause of additional fear and stress for some of the respondents. This is essential because of the restrictions that are applied for their and others' safety. In the case of the sports activities, some limitations are deriving from the same issue as it was with driving. There is a concern for public safety in case of the cycling and, according to one of the respondents, she was not recommended to ride a bike. Nevertheless, she chooses to do so, but she still considers the risks and her well-being. For the majority of the interviewed women, the sport is something that they need to try and to understand their body reaction to choose the proper activity. Regarding this issue, one woman said:

"The running is a little bit worse because the blood pressure is rising. I was at the gym and fainted twice because they said that I was lifting things, and acid was getting to my head. I was offered yoga, swimming, or running. Yoga is super, I am doing this. Swimming is also

interesting for me but running is different. I fainted once during this, and I think that I will stop doing that."

- Š, epilepsy onset at 18 y.o.

These results suggest that sport's impact on the overall QoL in women with epilepsy should be considered rather as a secondary factor as it is observed to a large extent as a way of relaxing and leisure time than a physical practice. The sports activities may improve the mental state among PWE, but they can also trigger an epileptic seizure. Therefore, medical consultation is required to understand the nature of epilepsy and the recommended sports. In that case, the additional fear and stress can be avoided, and, consequently, the benefits of physical exercising will be more apparent.

7.2.3. Health comorbidities

Due to the chronic nature of epilepsy, which often demands long-term usage of the AEDs, the health comorbidities are expected, according to Alfaro et al. (2019). In addition to that, I was interested, whenever women with epilepsy in this particular sample have other medical conditions that are affecting their QoL. Furthermore, my intentions were aimed to discover if respondents have any conditions that are linked to epilepsy besides psychiatric comorbidities. One of the respondents described her health in this way:

"I am having a cyst in the lungs and visit a doctor once a year, otherwise I am healthy."

- H, epilepsy onset at 14 y.o.

On the other hand, there are still some recommendations regarding the health of the respondents. For instance, one woman describes her limitations for various diets not as a restriction, but as advice from a doctor. The issue lies in the blood sugar level, which can trigger epileptic seizures. Furthermore, some respondents mentioned problems with thyroid and atopic eczema. Interestingly, they do not connect these issues to the long-term side effects of AEDs, even though there may be a correlation to the thyroid hormone dysfunction (Vincent, Crino 2011). In addition to that, atopic eczema and other allergic diseases considered to correlate with epilepsy (Silverberg, Joks, Durkin 2014; Chen et al. 2014).

Another health comorbidity for women with epilepsy can be related to the issue of pregnancy. It seems that epilepsy affected the QoL and the health of a new-born to some extent. Talking about health before and after the pregnancy in relation to epilepsy, she commented her first childbirth in the following way:

"After that, I had the early childbirth due to different problems. I think it was linked with epilepsy somehow, but nobody knew it for sure."

- D, epilepsy onset at 19 y.o.

Taken together, these results suggest that there is an actual impact on the QoL in the context of the health comorbidities, even though it is rather vulnerable. In addition to that, social life,

lifestyle adjustments, driving license, medications, pregnancy, and motherhood were recognized as primary factors based on the respondents' subjective QoL assessment. These primary factors were described as they were affecting the QoL to a more substantial extent in comparison with secondary factors. For instance, mental state, sport, and health comorbidities were identified as influential, but at the same time, their impact was not limiting the everyday life of the interviewed women with epilepsy. Furthermore, the influence of the primary factors has an effect not only on the current respondent's routine but also on their plans. On the other hand, secondary factors were frequently considered as temporary issues or did not originate from epilepsy. Further investigation regarding the health status of women with epilepsy will be needed to apprehend the issue in the context of the Czech PWE.

Chapter 8

8. Conclusion

This thesis has demonstrated that epilepsy has an influence on the QoL in women on the example of the Czech women's interviews that were analysed using the qualitative approach. Returning to the research questions that were posed at the beginning of this thesis, it is now reasonable to state that there are primary and secondary factors that affect the QoL in women with epilepsy based on their subjective evaluation. Furthermore, it was possible to see the value and the meaning of each factor that was introduced.

One of the most significant findings to emerge from this study is that specifics of the female health have an impact on the QoL with epilepsy. Because of that certain attention was taken into consideration linked to the past/hypothetical pregnancy and motherhood. Furthermore, due to specifics of the sample, where 5 out 6 women had been diagnosed with epilepsy before 18 years old, it was possible to explore relationships in the family, which were also influenced by epilepsy along with the adolescent years. It was also shown that driving is far more crucial for the Czech PWE than in similar QoL studies that were carried in different countries.

This thesis has found that, generally, the women with epilepsy perceived their QoL as satisfactory with several exceptions, such as the absence of the driving license, employment barriers, and restrictions regarding their social life in the past and the everyday routine in the present. The narrative analysis revealed that there was a notion of rebellion against medical recommendations and instructions concerning the sports activities.

The following conclusions can be drawn from the present study – there is a need for a future investigation of the QoL that will be focused on the above-mentioned factors for women with epilepsy. In addition to that, there is a strong notion of the lack of social understanding regarding the nature of this illness that results in the stereotypes, various myths, and, most importantly, stigma against PWE. An implication of this is the possibility that the future QoL quantitative studies among Czech women with epilepsy will take into account the significance of the driving

license that is linked to the issue of employment. Taken together, there is a need for a more thorough investigation of the social attitudes and knowledge about epilepsy as a chronic neurological disease in Czechia.

These findings enhance our understanding of the subjective perspective on women with epilepsy on their everyday life and overall well-being. The analysis of the primary and secondary factors undertaken here has extended our knowledge of the possible correlations between the low QoL score in women according to Bala et al. (2016). The present thesis confirms most previous findings and contributes additional evidence that suggests that there is a substantial influence of social support or the lack of this support on the QoL. Although the current analysis is based on a small sample of participants, the findings suggest the need for the demystification of epilepsy and lack of the information on basics of first aid during any kind of epileptic seizures.

The thesis has drawn upon many questions in need of further examinations. It would be noteworthy to compare the experience of individuals within the same sample characteristics, but with later onset of epilepsy. Besides, the comparison of the similar samples between different countries would be beneficial in testing the cultural and socioeconomic characteristics of the Czech PWE. Further research regarding the role of the potential or past pregnancies in women with epilepsy would be beneficial along with assessing the effect of AEDs on this issue in the context of the QoL. Another possible area of future research would be to investigate a similar sample regarding the onset of epilepsy but among male PWE. Considerably more work will need to be done to determine the impact of the driving license absence on the QoL and future employment in Czech PWE.

There are several crucial areas where this study makes an original contribution to the area of QoL in epilepsy research. This thesis offers some valuable insights into social and cultural specifics of the QoL in Czech by approaching the qualitative method, which is rarely practiced in epidemiological studies in Czechia. Furthermore, it advances the understanding of this concept related to women with epilepsy. In addition to that, this thesis provides an effort for the categorization of the impact factors based on the subjective assessment of the respondents from their standpoints.

The findings of this study have several essential implications for future practice. There is an apparent need for the more committed public awareness regarding the nature of epilepsy and the ways, in which a person can assist someone with an active epileptic seizure. This information can be used to develop targeted interventions aimed to reduce the myths about employment for Czech PWE. Taken together, these findings highlight the present need for future investigations of the QoL in Czech PWE from a qualitative perspective, especially for female PWE's current QoL and its possible development in the future.

Appendix 1 – semi-structured questionnaire (CZ)

Polostrukturovaný rozhovor

Vliv epilepsie na kvalitu života

Vytvořeno na základě QOLIE-31 a CHIS

1. Můžete mi krátce popsat svůj příběh?
   - Věk
   - Věk diagnózy
   - Národnost
   - Příčina
   - Druh epilepsie
   - Druh záchvatů
   - Frekvence epileptických záchvatů (počet záchvatů za posledních 12 měsíců)
   - Poslední záchvat (kdy)
   - Místo léčby
2. Popište, prosím, Váš život před tím, než Vám byla diagnostikována epilepsie.
   - Socioekonomický status
   - Domácnost – sám/s někým (s kým)
   - Rodinný stav
   - Vzdělání
   - Zaměstnání/studium (směr)
   - Zdravotní stav/situace PŘED diagnózou
3. Jak se nyní změnil Váš každodenní život?
   - Socioekonomický status
   - Zaměstnání (pokud ANO: směr)
   - Zdravotní stav (sebehodnocení)
   - Léky: minimálně jakého druhu, počet AE.
   - Nežádoucí účinky způsobené léky
   - Veřejná místa – řízení auta
4. Jaké aktivity jsou pro Vás omezené/nedostupné jen proto, že máte epilepsii?
   - Zaměstnání
   - Sport
   - Volný čas
   - Alkohol/kouření/drogy
   - Kamarádi a rodina (sociální izolace)
   - Dieta - ketodieta
5. Jaké omezení je Vámi považováno jako nejtěžší? (Proč?)
   Jak se s tím vypořádáte? Co děláte místo toho?
6. Co si myslíte o své kvalitě života s epilepsií v porovnání s ostatními (příbuzní, kamarádi)?
   Dohled, přehnaná péče, frustrace/úzkost, sociální izolace
7. Co byste chtel/a změnit/doplnit ve své léčbě?
   - Nežádoucí účinky AE.
   - Počet léků
   - Dohled jiných specialistů
   - Frekvence návštěv lékařů
8. Jak by vypadal Váš život bez epileptických záchvatů?
   - Zdravotní stav (sebehodnocení)
   - Zaměstnání
   - Vzdělání

- Sport
- Volný čas
- Dieta
- Kamarádi a rodina

Appendix 2 – informed consent (EN/CZ)

Informed consent

- ❑ I agree that I was informed of the aims of the conducted interview. I had the opportunity to ask for clarification if needed so.
- ❑ My participation in the interview is voluntary
- ❑ I agree to participate in the interview on the topic Epilepsy impact on the quality of life.
- ❑ I agree that the interview will be recorded and analyzed. Anonymized citations can be used in results of the master thesis. It will be impossible to identify me in any public results of the master thesis.
- ❑ I agree that the anonymized results of master thesis will be published.

Interviews are a part of the master thesis under the issue Epilepsy impact on the quality of life on the Faculty of Science of the Charles University.

Your rights are protected by the General Data Protection Regulation (GDPR). Interviews are anonymized in order to make unidentifiable the participated respondent. Personal data that are presented in the context of the interview will be used only for the translation and then deleted immediately after downloading the master thesis on the SIS (Students Information System).

The analysis of the interviews is aimed to bring an awareness of the quality of life in patients with epilepsy in the context of the master thesis.

If you have any questions or comments, please contact through the email: prudnike@natur.cuni.cz

Bc. Elizaveta Prudnikova

Respondent's initials	Date	Signature

Researcher's initials	Date	Signature

Informovaný souhlas

- ❑ Potvrzuji, že jsem byl/a obeznámen/a s cílem provedeného rozhovoru. Mel/a jsem možnost se zeptat na vzniklé nejasnosti.
- ❑ Rozhovoru se účastním dobrovolně.
- ❑ Souhlasím s účastí v rozhovoru na téma *Vliv epilepsie na kvalitu života*.
- ❑ Souhlasím s tím, že se mnou provedený rozhovor bude nahráván a analyzován. Anonymní citace mohou být použité v publikovaných výsledcích diplomové práce. V žádném z výsledků diplomové práce mne nebude možné identifikovat.
- ❑ Souhlasím s tím, že anonymizované výsledky diplomové práce budou publikovány.

Rozhovory se provádí v rámci diplomové práce na téma Vliv epilepsie na kvalitu života na Přírodovědecké fakultě Univerzity Karlově.

Vaše práva jsou chráněna Obecným nařízením o ochraně osobních údajů (GDPR). Rozhovory jsou anonymizované, takže z nich nebude možné zjistit, kdo poskytl informace. Osobní data poskytnutá v rámci rozhovoru budou použitá jen k přepisu a zničena ihned po odevzdání diplomové práci do Studentského Informačního Systému.

Cílem analýzy rozhovorů je zvýšení informovanosti o kvalitě života osob trpících epilepsií. Analýza bude provedena v rámci diplomové práci.

Pokud máte jakékoliv další otázky nebo komentáře, kontaktuje mě na e-mailovou adresu: prudnike@natur.cuni.cz

Bc. Elizaveta Prudnikova

Iniciály respondenta	Datum	Podpis

Jméno výzkumníka	Datum	Podpis

References

ADAMS, W. C. (2015): Conducting Semi-Structured Interviews. In: Handbook of Practical Program Evaluation: Fourth Edition.

AGRAWAL, N., BIRD, J. S., VON OERTZEN, T. J., COCK, H., MITCHELL, A. J., MULA, M. (2016): Depression correlates with quality of life in people with epilepsy independent of the measures used. Epilepsy and Behavior, 62, 246–250.

AGUIRRE, C., QUINTAS, S., RUIZ-TORNERO, A. M., ALEMÁN, G., GAGO-VEIGA, A. B., DE TOLEDO, M., VIVANCOS, J. (2017): Do people with epilepsy have a different lifestyle? Epilepsy and Behavior, 74, 27–32.

ALFARO, A., ASENSIO, M., GARCÍA-ESCRIVÁ, A., MEDRANO, V., SALOM, J. M., TORTOSA, D., PALAO, S., LEZCANO, M., BERENGUER, L., NAVARRO, M., CERDÁN, M., BUENDÍA, J. F., GINER, J. C. (2019): LAM study: Effects of lacosamide on behaviour and quality of life in patients with epilepsy. Neurologia, 1, 34, 1–6.

ALLISON, P. J., LOCKER, D., FEINE, J. S. (1997): Quality of life: A dynamic construct. Social Science and Medicine.

AYDEMIR, N., ÖZKARA, Ç., ÜNSAL, P., CANBEYLI, R. (2011): A comparative study of health related quality of life, psychological well-being, impact of illness and stigma in epilepsy and migraine. Seizure, 9, 20, 679–685.

BAKER, G. A., SMITH, D. F., DEWEY, M., JACOBY, A., CHADWICK, D. W. (1993): The initial development of a health-related quality of life model as an outcome measure in epilepsy. Epilepsy Research, 1, 16, 65–81.

BALA, A., SZANTROCH, M., GLEINERT, A., RYSZ, A., MARCHEL, A. (2016): Differences in quality of life of women and men with drug-resistant epilepsy in Poland. Epilepsy and Behavior, 60, 94–98.

BARAHMAND, U., HAJI, A. (2014): The impact of intolerance of uncertainty, worry and irritability on quality of life in persons with epilepsy: Irritability as mediator. Epilepsy Research, 8, 108, 1335–1344.

BISHOP, M., ALLEN, C. A. (2003): The impact of epilepsy on quality of life: A qualitative

analysis. Epilepsy and Behavior, 3, 4, 226–233.

BRIGO, F., BONAVITA, S., LEOCANI, L., TEDESCHI, G., LAVORGNA, L. (2020): Telemedicine and the challenge of epilepsy management at the time of COVID-19 pandemic.

CAMFIELD, P., CAMFIELD, C. (2015): Incidence, prevalence and aetiology of seizures and epilepsy in children. Epileptic Disorders, 2, 17, 117–123.

CARLTON-FORD, Steve, Robin MILLER, Matthew BROWN, Nichol NEALEIGH a Patricia JENNINGS. Epilepsy and Children's Social and Psychological Adjustment. Journal of Health and Social Behavior[online]. 1995, 36(3) [cit. 2019-09-29]. DOI: 10.2307/2137344. ISSN 00221465. Retrieved from: http://www.jstor.org/stable/2137344?origin=crossref

CARROZZINO, D., MORBERG, B. M., SIRI, C., PEZZOLI, G., BECH, P. (2018): Evaluating psychiatric symptoms in Parkinson's Disease by a clinimetric analysis of the Hopkins Symptom Checklist (SCL-90-R). Progress in Neuro-Psychopharmacology and Biological Psychiatry, 31, 81, 131–137.

CELANI, M. G., CANTISANI, T. A., BIGNAMINI, A., MACONE, S., PAPETTI, R., BAIOCCO, L. (2018): Is it worth it, or possible, to measure what matters to patients with epilepsy and their caregivers? Epilepsy and Behavior, 78, 273–279.

CHARYTON, C., ELLIOTT, J. O., LU, B., MOORE, J. L. (2009): The impact of social support on health related quality of life in persons with epilepsy. Epilepsy and Behavior, 4, 16, 640–645.

CHEN, H. F., TSAI, Y. F., HSI, M. S., CHEN, J. C. (2016): Factors affecting quality of life in adults with epilepsy in Taiwan: A cross-sectional, correlational study. Epilepsy and Behavior, 58, 26–32.

CHEN, M. H., WU, Y. H., SU, T. P., CHEN, Y. S., HSU, J. W., HUANG, K. L., LI, C. T., LIN, W. C., CHANG, W. H., CHEN, T. J., BAI, Y. M. (2014): Risk of epilepsy among patients with atopic dermatitis: A nationwide longitudinal study. Epilepsia.

CHENG, Y., LIU, C., MAO, C., QIAN, J., LIU, K., KE, G. (2008): Social support plays a role in depression in Parkinson's disease: A cross-section study in a Chinese cohort. Parkinsonism and Related Disorders, 1, 14, 43–45.

CHIU, M. J., CHEN, T. F., YIP, P. K., HUA, M. S., TANG, L. Y. (2006): Behavioral and psychologic symptoms in different types of dementia. Journal of the Formosan Medical Association, 7, 105, 556–562.

COLLARD, S. S., MARLOW, C. (2016): The psychosocial impact of exercising with epilepsy: A narrative analysis. Epilepsy and Behavior, 61, 199–205.

COULSON, N. S., BUCHANAN, H., AUBEELUCK, A. (2007): Social support in cyberspace: A content analysis of communication within a Huntington's disease online support group. Patient Education and Counseling, 2, 68, 173–178.

CRAMER, J. A., ARRIGO, C., VAN HAMMÉE, G., BROMFIELD, E. B. (2000): Comparison between the QOLIE-31 and derived QOLIE-10 in a clinical trial of levetiracetam. Epilepsy Research.

CRAWFORD, P. (2005): Best practice guidelines for the management of women with epilepsy.

DIENER, E., EMMONS, R. A., LARSEM, R. J., GRIFFIN, S. (1985): The Satisfaction With Life Scale. Journal of Personality Assessment.

ELLIOTT, I. M., LACH, L., SMITH, M. Lou (2005): I just want to be normal: A qualitative study exploring how children and adolescents view the impact of intractable epilepsy on their quality of life. Epilepsy and Behavior, 4, 7, 664–678.

ELLIOTT, J. O., LU, B., SHNEKER, B. F., MOORE, J. L., MCAULEY, J. W. (2009): The impact of "social determinants of health" on epilepsy prevalence and reported medication use. Epilepsy Research, 2–3, 84, 135–145.

ELLIOTT, J. O., MARES, A. S. (2012): Gender differences in quality of life among Canadian adults with epilepsy. Epilepsy Research, 1–2, 100, 42–48.

Epilepsy. WHO | World Health Organization [online]. Copyright © [cit. 03.08.2020]. Available from: https://www.who.int/news-room/fact-sheets/detail/epilepsy

EpiStop. Available from: https://www.epistop.cz

FELCE, D., PERRY, J. (1995): Quality of life: Its definition and measurement. Research in Developmental Disabilities.

FISHER, R. S., HELENCROSS, J., FRANCÉS, J., HIGURASHI, N., HIRSCH, E., JANSEN, F. E., MOSH, S. L., PELTOLA, J., ROULET, E., SCHEFFER, I. E., ZUBERI, S. M. (2017): Operativa de clasi fi cación de los tipos de convulsiones por la Liga Internacional contra la Epilepsia : Documento de posición de la ILAECommission de Clasi fi cación y Terminología. 522–530.

FISHER, R. S., NUNE, G., ROBERTS, S. E., CRAMER, J. A. (2015): The Personal Impact of Epilepsy Scale (PIES). Epilepsy and Behavior, 42, 140–146.

FRAADE-BLANAR, L. A., HANSEN, R. N., CHAN, K. C. G., SEARS, J. M., THOMPSON, H. J., CRANE, P. K., EBEL, B. E. (2018): Diagnosed dementia and the risk of motor vehicle crash among older drivers. Accident Analysis and Prevention.

FRENCH, J. A., BRODIE, M. J., CARABALLO, R., DEVINSKY, O., DING, D., JEHI, L., JETTE, N., KANNER, A., MODI, A. C., NEWTON, C. R., PATEL, A. A., PENNELL, P. B., PERUCCA, E., SANDER, J. W., SCHEFFER, I. E., SINGH, G., WILLIAMS, E., WILMSHURST, J., CROSS, J. H. (2020): Keeping people with epilepsy safe during the COVID-19 pandemic. In: Neurology.

FRIEDMAN, D. E., ISLAM, S., ETTINGER, A. B. (2013): Health-related quality of life among people with epilepsy with mild seizure-related head injuries. Epilepsy and Behavior, 3, 27, 492–496.

GAITATZIS, A., CARROLL, K., MAJEED, A., SANDER, J. W. (2004): The epidemiology of the comorbidity of epilepsy in the general population. Epilepsia.

GARCIA, M. E., GARCIA-MORALES, I., GIL-NAGEL, A. (2015): Prevalence of depressive symptoms and their impact on quality of life in patients with drug-resistant focal epilepsy (IMDYVA study). Epilepsy Research, 110, 157–165.

GEORGE, J., KULKARNI, C., SARMA, G. R. K. (2015): Antiepileptic drugs and quality of life in patients with epilepsy: A tertiary care hospital-based study. Value in Health Regional Issues, 6, 1–6.

GUTTER, T., CALLENBACH, P. M. C., BROUWER, O. F., DE WEERD, A. W. (2019): Prevalence of sleep disturbances in people with epilepsy and the impact on quality of life: A survey in secondary care. Seizure, April, 69, 298–303.

HEDMAN, R., HELLSTRÖM, I., TERNESTEDT, B. M., HANSEBO, G., NORBERG, A. (2014): Social positioning by people with Alzheimer's disease in a support group. Journal of Aging Studies, 1, 28, 11–21.

HERMAN, B. P. (1992): Quality of life in epilepsy. Journal of Epilepsy, 3, 5, 153–165.

HOLTKAMP, M., HAMERLE, M. (2015): Alcohol, nicotine, cannabis: Do stimulants trigger epileptic seizures? | Alkohol, Nikotin, Cannabis: Triggern Genussmittel epileptische Anfälle? Zeitschrift fur Epileptologie.

HORESH, D., BROWN, A. D. (2020): Covid-19 response: Traumatic stress in the age of Covid-19: A call to close critical gaps and adapt to new realities. Psychological Trauma: Theory, Research, Practice, and Policy.

HOYOS, M., DÍAZ-TORRES, M. A., DE LEÓN, R., IBARRA-YRUEGAS, B. E., CAMARA-LEMARROY, C. R. (2017): Affective symptoms and determinants of health-related quality of life in Mexican people with epilepsy. Neurological Sciences, 10, 38, 1829–1834.

JACOBY, A. (2002): Stigma , epilepsy , and quality of life. Health (San Francisco), 3, 10–20.

JACOBY, A., BAKER, G., SMITH, D., DEWEY, M., CHADWICK, D. (1993): Measuring the impact of epilepsy: the development of a novel scale. Epilepsy Research, 1, 16, 83–88.

JADHAV, P. M., BODKE, N. K., SANAP, D. A., GOGTAY, N. J. (2013): Assessment and comparison of health-related quality-of-life (HRQOL) in patients with epilepsy in India. Epilepsy and Behavior, 1, 27, 165–168.

JEHI, L., TESAR, G., OBUCHOWSKI, N., NOVAK, E., NAJM, I. (2011): Quality of life in 1931 adult patients with epilepsy: Seizures do not tell the whole story. Epilepsy and Behavior, 4, 22, 723–727.

JOHNSON, A. L., MCLEISH, A. C., SHEAR, P. K., SHETH, A., PRIVITERA, M. (2019): The role of cigarette smoking in epilepsy severity and epilepsy-related quality of life. Epilepsy and Behavior, 93, 38–42.

KADDUMUKASA, M., MUGENYI, L., LHATOO, S., SEWANKAMBO, N., BLIXEN, C., SAJATOVIC, M., KATABIRA, E. (2019): Seizure severity is associated with poor quality of life in people living with epilepsy (PLWE)in Uganda: A cross-sectional study. Epilepsy and Behavior, November 2017, 96, 104–108.

KALILANI, L., SUN, X., PELGRIMS, B., NOACK-RINK, M., VILLANUEVA, V. (2018): The epidemiology of drug-resistant epilepsy: A systematic review and meta-analysis. Epilepsia, 12, 59, 2179–2193.

KOVÁTS, D., CSÁSZÁR, N., HALLER, J., JUHOS, V., SALLAY, V., BÉKÉS, J., KELEMEN, A., FABÓ, D., RÁSONYI, G., FOLYOVICH, A., KURIMAY, T. (2017): Factors affecting quality of life in Hungarian adults with epilepsy: A comparison of four psychiatric instruments. Epilepsy and Behavior, 74, 45–58.

KUGOH, T. (1998): Quality of life research in adults with epilepsy in Japan. Clinical

Therapeutics, 20, A48–A57.

LEAHY, T., HENNESSY, M. J., COUNIHAN, T. J. (2018): The "Cinderella Syndrome": A narrative study of social curfews and lifestyle restrictions in juvenile myoclonic epilepsy. Epilepsy and Behavior, 78, 104–108.

LEE, K. E., LIM, K. H. (2019): Mediation Effect of Adaptation on the Quality of Life in Patients with Gastric Cancer Undergoing Gastrectomy: A Structure Equation Model. Asian Nursing Research, 1, 13, 38–46.

LEE, S. J., KIM, J. E., SEO, J. G., CHO, Y. W., LEE, J. J., MOON, H. J., PARK, S. P. (2014): Predictors of quality of life and their interrelations in Korean people with epilepsy: A MEPSY study. Seizure, 9, 23, 762–768.

LIM, Y. J., CHAN, S. Y., KO, Y. (2009): Stigma and health-related quality of life in Asian adults with epilepsy. Epilepsy Research, 2–3, 87, 107–119.

LIU, S. Y., HAN, X.-M., YAN, Y.-Y., SUN, B.-J., CHANG, Y. (2011): Quality of life and its influencing factors in patients with post-traumatic epilepsy. Chinese Journal of Traumatology - English Edition, 2, 14, 100–103.

LOUGHEED, J. P., KOVAL, P., HOLLENSTEIN, T. (2016): Sharing the burden: The interpersonal regulation of emotional arousal in mother-daughter dyads. Emotion.

LU, J. H., ZHOU, A. H., LI, F., HAO, Z. H., LI, W. J., CUI, Z. J., WANG, W. Q. (2013): Risk factors and characteristics of the recurrence of behavioral and psychological symptoms of Alzheimer's disease. Journal of Clinical Gerontology and Geriatrics, 4, 4, 115–118.

LUA, P. L., NENI, W. S. (2011): Awareness, knowledge, and attitudes with respect to epilepsy: An investigation in relation to health-related quality of life within a Malaysian setting. Epilepsy and Behavior, 3, 21, 248–254.

MAAS, A. H. E. M., APPELMAN, Y. E. A. (2010): Gender differences in coronary heart disease.

MAHRER-IMHOF, R., JAGGI, S., BONOMO, A., HEDIGER, H., EGGENSCHWILER, P., KRÄMER, G., OBERHOLZER, E. (2013): Quality of life in adult patients with epilepsy and their family members. Seizure, 2, 22, 128–135.

MANI, J. (2008): Temporal lobe epilepsy in children. 3, 2–6.

MARTINOVIĆ, Ž., MILOVANOVIĆ, M., TOŠKOVIĆ, O., JOVANOVIĆ, M., BUDER, N., SIMONOVIĆ, P., DOKIĆ, R. (2010): Psychometric evaluation of the Serbian version of the Quality of Life in Epilepsy Inventory-31 (QOLIE-31). Seizure, 8, 19, 517–524.

MCLAUGHLIN, D. P. (2011): Quality of life in epilepsy. In: Society, Behaviour and Epilepsy.

MCLAUGHLIN, D. P., PACHANA, N. A., MCFARLAND, K. (2008): Stigma, seizure frequency and quality of life: The impact of epilepsy in late adulthood. Seizure, 3, 17, 281–287.

MELIKYAN, E., GUEKHT, A., MILCHAKOVA, L., LEBEDEVA, A., BONDAREVA, I., GUSEV, E. (2012): Health-related quality of life in Russian adults with epilepsy: The effect of socio-demographic and clinical factors. Epilepsy and Behavior, 4, 25, 670–675.

MENDLOWICZ, M. V., STEIN, M. B. (2000): Quality of life in individuals with anxiety

disorders.

MICOULAUD-FRANCHÌ, J. A., BARTOLOMEI, F., DUNCAN, R., MCGONIGAL, A. (2017): Evaluating quality of life in epilepsy: The role of screening for adverse drug effects, depression, and anxiety. Epilepsy and Behavior, 75, 18–24.

MORÁŇ, Miroslav. Praktická epileptologie. 2. vyd. V Praze: Triton, 2007. ISBN 978-80-7387-023-2.

MORSY, N. E., FARRAG, N. S., ZAKI, N. F. W., BADAWY, A. Y., ABDELHAFEZ, S. A., EL-GILANY, A. H., EL SHAFEY, M. M., PANDI-PERUMAL, S. R., SPENCE, D. W., BAHAMMAM, A. S. (2019): Obstructive sleep apnea: Personal, societal, public health, and legal implications.

NADERIFAR, M., GOLI, H., GHALJAIE, F. (2017): Snowball Sampling: A Purposeful Method of Sampling in Qualitative Research. Strides in Development of Medical Education.

NESPOR, J. (2000): Anonymity and Place in Qualitative Inquiry. Qualitative Inquiry.

NOBLE, R. E. (2005): Depression in women. Metabolism: Clinical and Experimental.

PETERSEN, B., WALKER, M. L., RUNGE, U., KESSLER, C. (2004): Quality of life in patients with idiopathic, generalized epilepsy. Neurologie und Rehabilitation, 6, 10, 297–304.

PIAZZINI, A., BEGHI, E., TURNER, K., FERRARONI, M., AGUGLIA, U., ANTONINI, L., BENNA, P., FERRERO, M., BOGLIUN, G., CANEVINI, M. P., DANIELE, O., FRANCESCHETTI, S., CASAZZA, M., ARIENTI, F., GALLI, R., PIZZANELLI, C., GAMBARDELLA, A., GAROFALO, P. G., DURISOTTI, C., MAROTTI, E., GIALLONARDO, A. T., DI BONAVENTURA, C., GUIZZARO, A., IUDICE, A., BARTOLINI, E., MAGAUDDA, A., MALVEZZI, L., GIORGI, C., MAZZA, S., VACCARIO, M. L., MECARELLI, O., PULITANO, P., MUSOLINO, R., ONOFRJ, M., ORTENZI, A., PAGGI, A., ROCCHI, R., PUCCI, B., SPECCHIO, L. M., CASTRIOTA, O., STRIANO, S., STRIANO, P., TATA, M. R., TINUPER, P., BISULLI, F., LICCHETTA, L. (2008): Health-related quality of life in epilepsy: Findings obtained with a new Italian instrument. Epilepsy and Behavior, 1, 13, 119–126.

PODCASY, J. L., EPPERSON, C. N. (2016): Considering sex and gender in Alzheimer disease and other dementias. Dialogues in Clinical Neuroscience.

POPE, C. (2000): Qualitative research in health care: Analysing qualitative data. BMJ.

POPOVA, S., REHM, J., PATRA, J., ZATONSKI, W. (2007): Comparing alcohol consumption in central and eastern Europe to other European countries.

Quality of Life in Epilepsy Inventory (QOLIE-89 and QOLIE-31) | RAND. RAND Corporation Provides Objective Research Services and Public Policy Analysis | RAND [online]. Copyright © 1994 [cit. 17.08.2019]. Retrieved from: https://www.rand.org/health-care/surveys_tools/qolie.html

QUIGG, M., GHARAI, S., RULAND, J., SCHROEDER, C., HODGES, M., INGERSOLL, K. S., THORNDIKE, F. P., YAN, G., RITTERBAND, L. M. (2016): Insomnia in epilepsy is associated with continuing seizures and worse quality of life. Epilepsy Research, 122, 91–96.

RAMADAS, A., QURESHI, A. M., DOMINIC, N. A., BOTROSS, N. P., RIAD, A., THIRUNAVUK ARASOO, V. J., ELANGOVAN, S. (2015): Socio-demography and medical

history as predictors of health-related quality of life of breast cancer survivors. Asian Pacific Journal of Cancer Prevention.

RÄTY, L. K. A., SÖDERFELDT, B. A., WILDE LARSSON, B. M. (2007): Daily life in epilepsy: Patients' experiences described by emotions. Epilepsy and Behavior, 3, 10, 389–396.

RING, A., JACOBY, A., BAKER, G. A., MARSON, A., WHITEHEAD, M. M. (2016): Does the concept of resilience contribute to understanding good quality of life in the context of epilepsy? Epilepsy and Behavior, 56, 153–164.

ROSATI, A., DE MASI, S., GUERRINI, R. (2015): Antiepileptic Drug Treatment in Children with Epilepsy. Springer International Publishing, 29, 847–863.

SAADI, A., PATENAUDE, B., NIROLA, D. K., DEKI, S., TSHERING, L., CLARK, S., SHAULL, L., SORETS, T., FINK, G., MATEEN, F. (2016): Quality of life in epilepsy in Bhutan. Seizure, 39, 44–48.

SALE, J. E. M., THIELKE, S. (2018): Qualitative research is a fundamental scientific process. Journal of Clinical Epidemiology, 102, 129–133.

SANDER, Josemir, (2008). Gloal campaign against epilepsy: assessment of a demonstration project in rural China. *Bulletin of the World Health Organization* [online]. **86**(12), 964-969 [cit. 2020-07-26]. DOI: 10.2471/BLT.07.047050. ISSN 00429686. Retrieved from: http://www.who.int/bulletin/volumes/86/12/07-047050.pdf

SANGHERA, S., COAST, J. (2019): Measuring Quality-Adjusted Life-Years When Health Fluctuates. Value in Health, 1–5.

SANTOS, A. M. C., CASTRO-LIMA, H., MATOS, M. A. A., BRITO, M. B. (2018): Quality of life among women with epilepsy during their reproductive years. Epilepsy and Behavior, September 2017, 85, 10–13.

SCÉVOLA, L., SARUDIANSKY, M., LANZILLOTTI, A., ODDO, S., KOCHEN, S., D'ALESSIO, L. (2017): To what extent does depression influence quality of life of people with pharmacoresistant epilepsy in Argentina? Epilepsy and Behavior, 69, 133–138.

SCHEFFER, E., BERKOVIC, S., CAPOVILLA, G., CONNOLLY, M. B., FRENCH, J., GUILHOTO, L., HIRSCH, E., JAIN, S., MATHERN, G. W., MOSHÉ, S. L., NORDLI, D. R., PERUCCA, E., TOMSON, T. (2017): Classificazione delle epilessie della International League Against Epilepsy : position paper della Commissione ILAE per la Classificazione e la Terminologia. 4, 58, 512–521.

SHARP, N. L., BYE, R. A., CUSICK, A. (2019): Narrative analysis. In: Handbook of Research Methods in Health Social Sciences.

SHAW, I. (2008): Ethics and the practice of qualitative research. Qualitative Social Work.

SHULMAN, L. M. (2007): Gender differences in Parkinson's disease. Gender Medicine.

SIARAVA, E., HYPHANTIS, T., KATSANOS, A. H., PELIDOU, S. H., KYRITSIS, A. P., MARKOULA, S. (2019): Depression and quality of life in patients with epilepsy in Northwest Greece. Seizure, December 2018, 66, 93–98.

SILVA, S., FRAG, S. (2012): Qualitative Research in Epidemiology. Epidemiology - Current Perspectives on Research and Practice, 1994.

SILVERBERG, J. I., JOKS, R., DURKIN, H. G. (2014): Allergic disease is associated with epilepsy in childhood: A US population-based study. Allergy: European Journal of Allergy and Clinical Immunology.

Společnost E – podporujeme osoby s epilepsií, aby se lépe vypořádaly se svou nemocí. Available from: http://www.spolecnost-e.cz

SRIDHARAN, R., MURTHY, B. N. (1999): Prevalence and pattern of epilepsy in India. Epilepsia.

TABRIZI, N., ZARVANI, A., REZAEI, P., CHERAGHMAKANI, H., ALIZADEH-NAVAEI, R. (2019): Levetiracetam in genetic generalized epilepsy: A prospective unblinded active-controlled trial. Epilepsy Research, October, 157, 106214.

TAKAHASHI, S., SHIMIZU, K., INAJI, M., HASHIMOTO, S., YAMAMOTO, S., MAEHARA, T. (2019): Effectiveness of perampanel as a first add-on antiepileptic drug for the treatment of partial epilepsy. Epilepsy and Behavior, 100, 106492.

TEDRUS, G. M. A. S., STERCA, G. S., PEREIRA, R. B. (2017): Physical activity, stigma, and quality of life in patients with epilepsy. Epilepsy and Behavior, 77, 96–98.

TÉLLEZ-ZENTENO, J. F., DHAR, R., WIEBE, S. (2005): Long-term seizure outcomes following epilepsy surgery: A systematic review and meta-analysis.

TIAN, M., MA, W., CHEN, Y., YU, Y., ZHU, D., SHI, J., ZHANG, Y. (2018): Impact of gender on the survival of patients with glioblastoma. Bioscience Reports.

TLUSTA, E., KUBENA, A., SALEK, S., VLCEK, J. (2007): Psychometric properties of the Czech version of the Quality of Life in Epilepsy Inventory (QOLIE-31). Epilepsy & Behavior, 3, 10, 407–411.

TLUSTA, E., ZARUBOVA, J., SIMKO, J., HOJDIKOVA, H., SALEK, S., VLCEK, J. (2009): Clinical and demographic characteristics predicting QOL in patients with epilepsy in the Czech Republic: How this can influence practice. Seizure, 2, 18, 85–89.

TORALES, J., O'HIGGINS, M., CASTALDELLI-MAIA, J. M., VENTRIGLIO, A. (2020): The outbreak of COVID-19 coronavirus and its impact on global mental health.

TOWNSHEND, K. H., DORRIS, L., MCEWAN, M. J., AYLETT, S. E., BRODIE, M. J., O'REGAN, M., ESPIE, C. A. (2008): Development and validation of a measure of the impact of epilepsy on a young person's quality of life: Glasgow epilepsy outcome scale for young persons (GEOS-YP). Epilepsy and Behavior, 1, 12, 115–123.

UCLA CENTER FOR HEALTH POLICY RESEARCH (2013): California Health Interview Survey. <http://healthpolicy.ucla.edu/chis/pages/default.aspx>(accessed 16.08.14).

UNSWORTH, C. (1999): Living with epilepsy: Safety during home, leisure and work activities. Australian Occupational Therapy Journal.

VAN ROOIJEN, G., VAN ROOIJEN, M., MAAT, A., VERMEULEN, J. M., MEIJER, C. J., RUHÉ, H. G., DE HAAN, L., ALIZADEH, B. Z., BARTELS-VELTHUIS, A. A., VAN BEVEREN, N. J., BRUGGEMAN, R., CAHN, W., DELESPAUL, P., MYIN-GERMEYS, I., KAHN, R. S., SCHIRMBECK, F., SIMONS, C. J. P., VAN AMELSVOORT, T., VAN HAREN, N. E., VAN OS, J., VAN WINKEL, R. (2019): Longitudinal evidence for a relation

between depressive symptoms and quality of life in schizophrenia using structural equation modeling. Schizophrenia Research, 208, 82–89.

VENTEGODT, S., MERRICK, J., ANDERSEN, N. J. (2003): Quality of life theory I. The IQOL theory: an integrative theory of the global quality of life concept.

VILLANUEVA, V., GIRÓN, J. M., MARTÍN, J., HERNÁNDEZ-PASTOR, L. J., LAHUERTA, J., DOZ, M., CUESTA, M., LÉVY-BACHELOT, L. (2013): Quality of life and economic impact of refractory epilepsy in Spain: The ESPERA study. Neurología (English Edition), 4, 28, 195–204.

VINCENT, A., CRINO, P. B. (2011): Systemic and neurologic autoimmune disorders associated with seizures or epilepsy.

WIJNEN, B. F. M., SCHAT, S. L., DE KINDEREN, R. J. A., COLON, A. J., OSSENBLOK, P. P. W., EVERS, S. M. A. A. (2018): Burden of disease of people with epilepsy during an optimized diagnostic trajectory: costs and quality of life. Epilepsy Research, April, 146, 87–93.

WOLF, L. D., HENTZ, J. G., ZIEMBA, K. S., KIRLIN, K. A., NOE, K. H., HOERTH, M. T., CREPEAU, A. Z., SIRVEN, J. I., DRAZKOWSKI, J. F., LOCKE, D. E. C. (2015): Quality of life in psychogenic nonepileptic seizures and epilepsy: The role of somatization and alexithymia. Epilepsy and Behavior, 43, 81–88.

WORLD HEALTH ORGANIZATION (2019): WHO | Epilepsy: a public health imperative.

YAGI, K. (1998): Epilepsy: comprehensive care, quality of life, and factors preventing people with epilepsy from being employed. Clinical Therapeutics, 20, A19–A29.

YENI, K., TULEK, Z., SIMSEK, O. F., BEBEK, N. (2018): Relationships between knowledge, attitudes, stigma, anxiety and depression, and quality of life in epilepsy: A structural equation modeling. Epilepsy and Behavior, 85, 212–217.

YUE, L., YU, P. min, ZHAO, D. hao, WU, D. yan, ZHU, G. xing, WU, X. yi, HONG, Z. (2011): Determinants of quality of life in people with epilepsy and their gender differences. Epilepsy and Behavior, 4, 22, 692–696.

Zákon o silničním provozu (zákon č. 361/2000 Sb., o provozu na pozemních komunikacích). Zákony online [online]. Available from: http://zakony-online.cz/?s38&q38=all

ZEIN, J. G., ERZURUM, S. C. (2015): Asthma is Different in Women.

ZIEGLER, Robert G. Epilepsy: Individual Illness, Human Predicament and Family Dilemma. Family Relations [online]. (1982), 31(3) [cit. 2019-09-29]. DOI: 10.2307/584177. ISSN 01976664. Retrieved from: https://www.jstor.org/stable/584177?origin=crossref